



Gynaecological cancer follow-up: National survey of current practice in the UK

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Gynaecological cancer follow-up national survey of current practice

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Key words: neoplasm, questionnaires, female continuity of patient care/standards, survivorship, neoplasm recurrence



Abstract

Objective

To establish a baseline of national practice for follow-up after treatment for gynaecological cancer.

Design

Questionnaire survey.

Setting

Gynaecological cancer centres and units.

Geographical location

UK

Participants

Members of the British Gynaecological Cancer Society and the National Forum of Gynaecological Oncology Nurses.

Interventions

A questionnaire survey was circulated to enquiring about schedules of follow-up, who provides it and what routine testing is used.

Outcome measures

To determine if follow-up could be modified to improve the survivorship experience for patients who have had previous gynaecological cancer.

Results

A total of 117 responses were obtained; 115 (98%) reported hospital scheduled regular follow-up appointments. Two involved General Practitioners. Follow-up was augmented or replaced by telephone follow-up in 29 (25%) and patient initiated appointments in 38 responses (32%). A total of 88 (68%) cancer specialists also offered combined follow-up clinics with other specialties. Clinical examinations for hospital based follow-up are mainly performed by doctors (67% for scheduled regular appointments and 63% for patient initiated appointments) while telephone follow-up care is provided in the majority by nurses (76%). Most respondents provide routine tests (76/117 (65%)), from which 66/76 (87%) reported carrying out surveillance tests for ovarian cancer, 35/76 (46%) for cervical cancer, 8/76 (11%) for vulval cancer and 7/76 (9%) for endometrial cancer. Usually patients were discharged after five years (82/117 (70%)), whereas three (3%) were discharged after four years, nine (8%) after three and one (1%) after two years.

Conclusions

Practice varied but most used a standard hospital based protocol of appointments for five years and routine tests were performed usually for women with ovarian cancer. A minority utilised nurse-led or telephone follow-up. General Practitioners were rarely involved in routine care. A randomised study comparing various models of follow-up could be considered.

289 words

Article summary**Article focus**

- Follow-up after treatment for cancer is a resource intense area of clinical practice which does not have clear benefits for patients.
- Doctors and nurses involved in care for women with gynaecological cancer were invited to respond to a questionnaire survey.
- A survey is presented of current follow-up after treatment for gynaecological cancer in the UK.

Key messages

- There is a variation of follow-up practice throughout the UK.
- A minority used nurse led or telephone follow-up as opposed to a conventional series of hospital outpatient appointments to see a doctor.

Strengths and limitations of this study

- A strength is that this is the first study to report the use of patient initiated, specialist nurse or telephone follow-up for gynaecological cancer in the UK.
- A limitation is that four UK cancer networks did not respond.

Introduction

Traditionally, patients who have had treatment for cancer are kept on regular review in hospital out-patient clinics for a period of between five to 10 years after completion of their treatment. The aims may be to detect recurrence of tumour, to monitor late effects of treatment, to collect data and to offer patients an opportunity to raise concerns or anxieties arising from their cancer. The assumption behind this approach is that early detection of recurrence will be of benefit to the patient and that monitoring side-effects and anxieties will allow helpful interventions that will improve the patient's quality of life.

Routine follow-up is a time-consuming and expensive process with many hundreds of patients attending clinics in each hospital each year at an NHS tariff of £118 per visit (Department of Health, 2011). In Wales alone we estimate the cost of this follow up is in excess of £1m annually. If the object is the early detection of recurrent disease, studies investigating recurrence for breast cancer reported most recurrences presenting between scheduled clinic appointments (Pandya *et al*, 1985; Scanlon *et al*, 1980; Brøyn and Frøyen, 1982; Winchester *et al*, 1979; Zwaveling *et al*, 1987; Grunfeld *et al*, 1996) and gynaecological patients may wait for their next routine appointment to disclose their symptoms (Olaitan *et al*, 2001). A cost benefit analysis for endometrial carcinoma showed that one asymptomatic recurrence was detected in every 653 consultations (Salvesen *et al*, 1997). In a review of 12 studies, only 30% of endometrial cancer recurrences were asymptomatic and methods of follow-up were unrelated to survival (Fung-Kee-Fung *et al*, 2006). As around 20% of all female cancer survivors have had gynaecological malignancy a cost effective form of surveillance is important (Salani *et al*, 2011).

In clinical practice there appears to be no rationale available for any particular follow-up protocol (Sartori *et al*, 2010). Rapid access to oncological assessment at recurrence may be more important than offering frequent routine appointments. Given that patients wish to be cured of their disease and that different schedules of follow-up do not appear to have an impact upon survival, delegation of routine follow-up could be to other carers. Telephone consultations can free oncologists' clinic time and is convenient for patients. Follow-up may be in primary care, a hospital based nurse led clinic, by telephone or at the request of the patient. Despite its place in standard healthcare the benefits of routine follow-up following treatment for cancer has received little scrutiny and has rarely been subjected to formal assessment.

In order to determine a baseline of current practice for gynaecological cancer follow-up in the United Kingdom, we have performed a survey of cancer follow-up in gynaecological oncology. The aim is to investigate who performs follow-up, for what duration and how this is achieved to see if there is a possibility to improve the quality of care offered to patients after their cancer treatment.

Materials and methods

The follow-up survey was designed using the Bristol Online Survey (BOS) to provide electronic data capture and data management support to the questionnaire. The BOS is an easy-to-use survey tool, which allows developing, deploying and analysing surveys via the internet. The dataset was managed by the Information Systems Department at the North Wales Organisation of Randomised Trials (Bangor University). Data was anonymised and then exported to the databases held in SPSS™ (version

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3 18.0; SPSS, Chicago, IL). The e-survey targeted gynaecological cancer experts in all cancer networks in
4 the United Kingdom. It was available online using an electronic web link from June to September 2012.
5 An initial invitation email and a reminder with the web link were sent through the Principal
6 Investigator (PI) distribution list of the British Gynaecological Cancer Society (BGCS) and National
7 Forum of Gynaecological Oncology Nurses (NFGON) members. A news release published in June 2012
8 on the BGCS website also invited members to take part in the survey.
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11 The investigators in consultation with the BGCS and a patient representative designed the
12 questionnaire which was organised around three themes (see questionnaire in appendix). The first
13 comprised questions related to practice setting (i.e. organisation and hospital) and respondent
14 characteristics (i.e. profession and medical specialty). The second comprised questions related to the
15 use of standard protocols for follow-up. The bulk of the questionnaire addressed information about
16 the different schedules of follow-up and which surveillance tests were used routinely in follow-up
17 practices for different type of cancers. We listed four possible types of follow-up appointments;
18 clinician-led (traditional), nurse-led, telephone follow-up and patient initiated follow-up. Telephone
19 follow-up appointments were defined as a pre-arrangement for a member of the cancer team to
20 contact the patient by telephone without a need for the patient to attend hospital. Patient initiated
21 follow-up was defined as practice where the patient is not followed-up in secondary care but seen
22 only if the patient requests or initiates a contact, for example if they are worried about a suspicion of
23 recurrent disease.
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28 Most answers were recorded as a binary variable (yes/no answer) with additional, open text box
29 response options throughout the questionnaire for comments and alternative suggestions.
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31 Data was collated and presented as numbers and a percentage of applicable denominators. The
32 geographical spread of responses was mapped. Textual answers were categorised and counted.
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37 Results

38 *Sample size and respondents characteristics*

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40 Responses were received from 118 experts in gynaecological cancer drawn from the membership of
41 the BGCS and NFGON. Because the survey was conducted online with the request to take part
42 distributed widely by email it is impossible to state how many had the opportunity to take part but did
43 not. Therefore the response rate has not been calculated. Nonetheless we received responses from
44 86% (24/28) of the cancer networks in England and all cancer networks in Wales (two), Scotland
45 (three) and Northern Ireland (one). One response was received from a surgical oncologist based in
46 Greece who has been excluded from the study as the objective is assessing current practice of follow-
47 up after gynaecological cancer treatment in the UK. Of the 117 cancer specialists included in the study,
48 71 (61%) worked in a cancer centre, 32 (27%) in a cancer unit and 12 (10%) reported working in both.
49 Eighty-eight (75%) of the respondents were surgical oncologists. Fifteen (13%) were clinical oncologists
50 and six (5%) were specialised in medical oncology. The majority of the respondents (83 (71%)) were
51 doctors while nurses constituted less than a third of the sample (32 (27%)). Full results are presented
52 in table 1.
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Standard follow-up protocols

All respondents with the exception of one surgical oncologist (116/117 (99%)) reported that they had a standard follow-up protocol after completion of treatment. However all 30 networks providing responses had at least one respondent reporting having protocols for follow-up. The vast majority of respondents provided follow-up in secondary care, only two respondents (from different English cancer networks) reported that visits to primary care are part of their follow-up routine.

Most 87/116 (75%) of the respondents reported using different follow-up protocols for different tumour sites (eg. cervix and ovary) and 35/116 (30%) reported having a different protocol for different tumour types (eg. well or poorly differentiated). On a cancer network basis, identical protocols for different tumour sites were reported in 16 networks. Identical protocols for different tumour types were reported by respondents from 23 of the 24 English networks, both of the Wales networks, the Northern Ireland network, and one of the cancer networks in Scotland.

Composition follow-up appointments

All respondents in our sample reported they follow-up patients after completion of gynaecological cancer treatment. One hundred and fifteen (98%) reported hospital scheduled regular follow-up appointments from which the patient may be discharged if she remains disease free after a specified period of time. This follow-up was augmented or replaced by a telephone follow-up in 29 (25%) and patient initiated appointments in 38 responses (32%). A combination of regular, telephone or patient initiated follow-up was available from 33 respondents and of these 19 (58%) reported patients could attend either a medical or a nurse led clinic. However, 6/19 (32%) did not have a protocol to allocate patients to each clinic. For patient initiated appointments, 10/38 (26%) of the specialists did not have a protocol with contact details (eg. a secretary, Macmillan nurse or General Practitioner) for self-referrals. A total of 88/117 (68%) cancer specialists also offered combined follow-up clinics with other specialties (eg. combined surgical and medical oncology or surgical and clinical oncology clinics).

Virtually all respondents reported in the case of sudden events that symptomatic patients could arrange an appointment in less than two weeks. Seven (6%) respondents from five different cancer networks answered that their practices schedule urgent appointments in a period of two to four weeks, from which two of them also scheduled urgent patient initiated appointments in the same timeframe.

Follow-up in hospital is mainly performed by doctors (67% for scheduled regular appointments and 63% for patient initiated appointments) while telephone follow-up care is provided in its majority by nurses (76%). Full details are illustrated in table 2.

Duration of follow-up and surveillance tests

The survey asked respondents whether they perform any type of routine follow-up or surveillance test during follow-up. Routine tests are provided by 65% (76/117) of respondents, from which 87% (66/76) reported carrying out tests for ovarian cancer, 46% (35/76) for cervical cancer, 11% (8/76) for vulva

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3 cancer and nine per cent (7/76) for endometrial cancer. In addition, respondents were asked to
4 provide details of when these tests are performed but only a few responses were obtained. Table 3
5 shows the distribution of the different type of tests employed during follow-up.
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8 CA125 measurement was the most frequently used test (60/66 (91%)) during follow-up of ovarian
9 cancer patients followed by other blood tests (8/66 (12%)), eg. alpha-fetoprotein , carcino-embryonic
10 antigen , CA19.9 and inihibin. The routine use of computed tomography and magnetic resonance
11 imaging (MRI) scans for ovarian cancer were reported by 9/66 (14%) of the respondents (one
12 respondent used both CT and MRI). Eight cancer specialists stated the CA125 test is performed at each
13 visit. Another seven specialists reported the CA125 is performed every three months for the first year
14 after completion of treatment, from which two of them reported they carry on with routine testing for
15 the second year and four up to year five every six months.
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18 The use of MRI (15/35 (43%)) was the most common investigation employed in the follow-up of
19 cervical cancer with cervical or vaginal cytology being the second commonest method (14/35 (40%)).
20 There was a wide variety of tests (8/35 (23%)) reported in the follow-up of this type of cancer. Two of
21 the respondents stated they perform vault cytology for cervical cancer patients annually for a period
22 of five years following hysterectomy, while three specialists reported carrying out the test at six and
23 18 months post-treatment.
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26 Most respondents discharged their patients after five years of follow-up (82/117 (70%)), three (3%)
27 after four years, nine (8%) after three and one (1%) after two years whereas 22/117 (19%) of
28 respondents did not answer this question.
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31 32 33 Discussion

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35 The current survey is the first evidence reporting the extent of patient initiated, specialist nurse or
36 telephone follow-up for gynaecological cancer in the UK. Our survey also shows that all gynaecological
37 cancer networks providing responses have protocols for follow-up after treatment. Follow-up for
38 patients treated for gynaecological cancer is mainly performed by doctors in secondary care. There are
39 few routine tests undertaken during follow-up to detect recurrence and they show no consistency
40 particularly for cervical cancer. Of the 35 respondents who requested tests for cervical cancer follow-
41 up, 15 (43%) requested MRI and 14 (40%) requested cytology. Such variation is not surprising with the
42 lack of evidence to guide clinical management. The exception is CA125 testing following treatment for
43 ovarian cancer where 52% of all respondents recommended CA125 monitoring despite grade one
44 evidence to demonstrate that routine CA125 measurements do not benefit asymptomatic patients
45 having had ovarian cancer (Rustin *et al*, 2010). Furthermore, there appears to have been no recent
46 change of this practice in our survey, as monitoring with CA125 testing was reported in 24 of the 34
47 networks (71%) whereas 67% of networks recommended such testing in an earlier survey (Kew and
48 Cruickshank, 2006). Patient initiated follow-up was offered by 32% of respondents and telephone
49 follow-up was offered by 25%. A large minority of patient initiated follow-up and combined follow-up
50 schedules did not have protocols to guide practice. The most common duration of routine follow-up is
51 for five years.
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3 Vistad *et al* (2012) also published results of a web-based survey of practice amongst gynaecological
4 oncologists across Europe and reported that 47% of the 375 respondents considered follow-up with
5 General Practitioners to be acceptable. Other options for care were not considered and the response
6 rate was thought to be below 20%. However there appears to be little or no evidence upon which to
7 guide follow-up for gynaecological malignancy from the survey by Vistad *et al*, the earlier survey from
8 the UK (Kew and Cruickshank, 2006) and from our work.
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11 From other research, patients with previous ovarian cancer rated CA125 testing as the most important
12 part of follow-up despite the knowledge that routinely measuring the CA125 value does not improve
13 survival (Rustin *et al*, 2010). Furthermore knowledge of recurrence whether treatable or not appears
14 useful to patients (Kew *et al*, 2009) and information should be provided to detail the scope and
15 limitations of follow-up (Kew *et al*, 2007). Rapid access to oncological assessment at recurrence may
16 be more important than offering frequent routine appointments. Given that patients wish to be cured
17 of their disease and knowing that different schedules of follow-up do not have an impact upon
18 survival, delegation of routine follow-up could be to other carers (Vistad *et al*, 2012). Follow-up may
19 be in primary care, a hospital based nurse led clinic, by telephone or at the request of the patient. An
20 individualised approach to follow-up is likely to be important to concentrate care for those perceived
21 to be at a greater risk of recurrent disease or other issues of survivorship. This may include a risk
22 assessment where there are effective interventions for physical, psychological and social issues as well
23 as needs assessments which are clearly patient centred as defined by the National Cancer Survivorship
24 Initiative (Watson *et al*, 2012) whilst bearing in mind that a minority of patients may be cured with
25 further therapy. Follow-up has to be multidisciplinary, designed for risk of recurrence and with good
26 communication between professional groups. Informed patient choice regarding mode and frequency
27 of follow-up is important. Reducing the frequency of follow-up appointments may not place an
28 increased demand upon unnecessary patient initiated extra hospital appointments and patients may
29 prefer fewer appointments (Gulliford *et al*, 1997). The ideal time of advising a patient about a
30 preferred form of follow-up is unclear but may be shortly after all modalities of treatment have been
31 completed.
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38 North Wales Organisation for Randomised Trials in Health in collaboration with several leading
39 gynaecological oncologists has previously developed a proposal for a randomised study to assess the
40 value of hospital follow-up of endometrial cancer (Follow-up in Gynaecological Cancer Units: RCT for
41 Endometrium or FIGURE). The proposal was for a multicentre, randomised trial comparing standard
42 (hospital) follow-up with patient initiated review. The endpoints were to be quality of life and survival
43 with a planned recruitment of 2200 patients to detect an effect size of 0.2. Unfortunately, although
44 the proposal was well received, it was impossible to agree a level of funding to allow the study to
45 proceed. More recently the Endometrial Cancer Telephone Follow-up Trial (ENDCAT ISRCTN
46 75220876) has started. This is a study comparing traditional hospital follow-up with telephone follow-
47 up by specialist gynaecology oncology nurses with primary outcomes of psychological morbidity and
48 patient satisfaction. Again this is a randomised trial for endometrial cancers only and is at a single
49 centre. It is currently recruiting to schedule and is due to close in 2014. A Trial between Two Follow-up
50 Regimens with Different Intensity in Endometrial Cancer Treated Patients (TOTEM NCT00916708) is a
51 further ongoing but multicentre randomised trial in Italy, comparing overall survival, progression free
52 survival, complications, proportion of asymptomatic relapse and the proportion of patients completing
53 each regimen for follow-up. It is due to close in 2015.
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3 Current trial activity suggests a trial similar to FIGURE should be revisited but to include follow-up for
4 more than one gynaecological cancer site. Practice has already begun to change to include patient
5 initiated follow-up for gynaecological cancer patients but our survey has demonstrated that these
6 changes are not yet widespread. However, the evidence base for changing practice to a less intensive
7 follow-up programme for gynaecological cancer is poor and Vistad *et al* (2011) reported no
8 randomised studies on this subject. The current scoping study has demonstrated that the vast
9 majority of follow-up still reflects traditional patterns, with only about a third of practitioners
10 incorporating more flexible follow-up routines into their practice. In our current constrained financial
11 environment, to continue to use patterns of follow-up for gynaecological cancers which are neither
12 evidence-based nor affordable is inappropriate. We aim to develop a suite of pilot and feasibility
13 studies that may lead to a UK multicentre randomised controlled trial to assess the clinical benefits
14 and costs of routine hospital follow-up in comparison with the patient being empowered to choose
15 her preferred format of follow-up for most gynaecological cancers. This would incorporate
16 information with contact details and about the possible symptoms of recurrence, with formal review
17 only as and when required by the patient. The current survey is the first in this series in assessing
18 current national practice.
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2918 words

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26

27 Authors' roles

28
29 Simon Leeson final manuscript preparation, review of data, design of questionnaire
30 Nick Stuart draft script development, design of questionnaire
31 Yvonne Sylvestre review of data
32 Liz Hall draft script development
33 Rhiannon Whitaker draft script development, review of data, design of questionnaire
34
35

36 Competing interest

37 No, there are no competing interests.
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39

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41 No, this research received no specific funding.
42
43

44 Data sharing

45 The raw data has been archived at NWORD Clinical Trials Unit and will be available to interested
46 researchers by agreement with the Principal Investigator.
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Table 1: Characteristics of respondents (N=117)

	N (%)
Region	
England	102 (87%)
Wales	7 (6%)
Scotland	5 (4%)
Northern Ireland	3 (3%)
Organisation	
Cancer centre	71 (61%)
Cancer unit	32 (27%)
Cancer unit & cancer centre	12 (10%)
Other ¹	2 (2%)
Specialty	
Surgical oncology	73 (62%)
Medical oncology	6 (5%)
Clinical oncology	15 (13%)
Surgical & medical oncology	6 (5%)
Surgical & clinical oncology	1 (1%)
Surgical, medical & clinical oncology	8 (7%)
Other ²	8 (7%)
Profession	
Medical	83 (71%)
Nursing	32 (27%)
Other ³	2 (2%)

1. Includes gynaecology unit in a chemo centre (n=1) and hospital (n=1).

2. Includes clinical nurse specialist (n=2), nursing (n=2), gynaecology (n=2), gynaecology & surgical oncology (n=1) and pathology (n=1).

3. Includes consultant radiographer (n=1) and missing response (n=1).

Table 2: Type and frequency of occurrence of differing modes of follow-up

	Regular	Telephone	Patient initiated
Positive responses	115/117 (98%)	29/117 (25%)	38/117 (32%)
Urgent follow-up bookings			
< 2 weeks	108/115 (94%)	29/29 (100%)	35/38 (92%)
2 to 4 weeks	7/115 (6%)	0 (0%)	2/38 (5%)
Responsible for follow-up			
Doctors	77/115 (67%)	4/29 (14%)	24/38 (63%)
Nurses	0 (0%)	22/29 (76%)	2/38 (5%)
Doctors & nurses	36/115 (31%)	3/29 (10%)	11/38 (29%)
Other ¹	2/115 (2%)	1/29 (3%)	1/38 (3%)

1. Includes radiographer (n=1), consultant radiographer (n=1), for regular appointments; specialist radiographer (n=1) for telephone appointments and missing response (n=1) for patient initiated appointments.

Table 3: Frequency of surveillance tests reported by type of test and cancer type

	Ultrasound [†]	CA125	Other blood tests*	CT	MRI	Cytology	Other [¶]	Total
Ovarian	5	60	8	5	4	0	0	82
Cervical	1	0	4	0	15	14	3	37
Endometrial	1	1	0	0	1	1	0	4
Vulval	0	0	0	0	1	0	4	5

Key: CA125, cancer antigen 125; CT, computed tomography; MRI, magnetic resonance imaging.

[†] Ultrasound includes: abdominal and transvaginal ultrasound.

* Other blood tests includes: other tumour markers (n=8) for ovarian cancer and squamous cancer antigen (n=3) for cervical cancer.

[¶] Other includes: colposcopy (n=2) for cervical cancer and vulvoscopy (n=3) for vulval cancer.

Appendix: Gynaecological cancer follow-up survey of current practice

Introduction

Patients may appreciate the attention given to follow up after treatment for cancer yet the survival benefit of follow up is unclear. We are planning to review local practice to determine if follow up to detect recurrence at an early stage can improve survival. However a preliminary assessment of national practice would be ideal. A prospective study of follow up strategies may follow. We would appreciate a few minutes of your time as cancer specialists to complete the following questionnaire.

Questions

Q1. In which cancer network do you work?

Q2. Where do you work?

- i. Cancer Centre
- ii. Cancer unit
- iii. Other (please specify)

Q3. Please enter name of the hospital (s) at which you work? (Optional)

Q4. Is your work within surgical, medical or clinical oncology or another discipline?

- i. Surgical oncology
- ii. Medical oncology
- iii. Clinical oncology
- iv. Imaging
- v. Pathology
- iv. Other (please specify)

Q4.a. What is your profession?

- i. Medical
- ii. Nursing
- iii. Other (please specify)

Q5. Do you have a standard follow up protocol following completion of treatment for gynaecological cancer?

- i. Yes
- ii. No
- iii. Don't know

Q5a. Do you have a different protocol for different tumour sites e.g. cervix and ovary?

- i. Yes
- ii. No
- iii. Don't know

Q5b. Do you have a different protocol for different tumour types e.g. well or poorly differentiated?

- i. Yes
- ii. No
- iii. Don't know

Q5c. Does the routine follow-up involve visits to primary care?

- i. Yes
- ii. No
- iii. Don't know

Q6. Do you have regular follow-up appointments? Regular follow-up appointments here means an agreed schedule of visits from which the patient may discharge if she remains disease free after a specified period of time.

- i. Yes
- ii. No
- iii. Don't know

Q6a. If so, when can you book urgent follow-up appointments for symptomatic patients?

- i. In less than 2 weeks
- ii. 2-4
- iii. 4+ weeks
- iv. Don't know

Q6b. Who provides the follow-up?

- i. Nurses
- ii. Doctors
- iii. Don't know
- iv. Other (please specify)

Q7. Do you have telephone follow-up appointments? A telephone follow-up appointment is an appointment pre-arranged for a member of the cancer team to contact the patient by telephone without a need for the patient to attend hospital.

- i. Yes
- ii. No
- iii. Don't know

Q7a. If so when can you book urgent follow-up appointments for symptomatic patients?

- i. In less than 2 weeks
- ii. 2-4
- iii. 4+ weeks
- iv. Don't know

Q7b. Who provides the follow-up?

- i. Nurses
- ii. Doctors
- iii. Don't know
- iv. Other (please specify)

Q8. Do you have patient initiated follow-up appointments? Patient initiated follow-up is when the patient is not followed-up in secondary care but sees only if the patient requests (such as suspicion of recurrent disease).

- i. Yes
- ii. No
- iii. Don't know

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2
3 Q8a. Do you have a protocol for asking patients to self-refer with contact details (e.g. a secretary,
4 Macmillan Nurse or her GP)?

- 5
6 i. Yes
7 ii. No
8 iii. Don't know
9

10 Q8b. If so, can urgent appointments for symptomatic patients be booked? To see the patient

- 11 i. In less than 2 weeks
12 ii. 2-4
13 iii. 4+ weeks
14 iv. Don't know
15

16 Q8c. Who provides the follow-up?

- 17 i. Nurses
18 ii. Doctors
19 iii. Don't know
20 iv. Other (please specify)
21
22

23 Q9. Do you have a combination of regular follow-up, telephone follow up and/ or patient initiated
24 follow-up appointments?

- 25 i. Yes
26 ii. No
27 iii. Don't know
28
29

30 Q9a. Do you have a follow-up where patients attend either a medical or a nurse led clinic?

- 31 i. Yes
32 ii. No
33 iii. Don't know
34

35 Q9b. If yes, do you have a protocol to allocate patents to each clinic?

- 36 i. Yes
37 ii. No
38
39

40 Q10. Do you have combined follow-up clinics with other specialties (e.g. combined surgical and
41 medical oncology, surgical and clinical oncology clinics)?

- 42 i. Yes
43 ii. No
44 iii. Don't know
45

46 Q10a. If yes please specify

- 47 i. Clinical
48 ii. Medical
49 iii. Surgical oncology
50
51

52 Q11. During follow-up do you carry out certain blood tests (e.g. CA125), vault cytology or imaging
53 such as CT or MR routinely for cases at a certain time interval?

- 54 i. Yes
55 ii. No
56 iii. Don't know
57
58
59
60

1
2
3 Q11a. Ovary

- 4 i. Yes
5 ii. No
6

7 Q11a.i. Please provide details of which tests and when these are usually carried if possible
8

9 Q11b. Cervix

- 10 i. Yes
11 ii. No
12

13 Q11b.i. Please provide details of which tests and when these are usually carried if possible
14

15 Q11c. Endometrium

- 16 i. Yes
17 ii. No
18

19 Q11c.i. Please provide details of which tests and when these are usually carried if possible
20

21 Q11d. Vulva

- 22 i. Yes
23 ii. No
24

25 Q11d.i. Please provide details of which tests and when these are usually carried if possible
26

27 Q11e. Other

- 28 i. Yes
29 ii. No
30

31 Q11e.i. Please provide details of which tumour site(s)

32 Q11e.i.i. Please provide details of which tests and when these are usually carried if possible
33

34 Q12. After how many years of follow up are patients usually discharged?

- 35 i. 1
36 ii. 2
37 iii. 3
38 iv. 4
39 v. 5
40 vi. 6
41 vii. 7
42 viii. 8
43 ix. 9
44 x. 10
45 xi. 10+
46 xii. Never
47 xiii. N/A
48 xiv. Other(please specify)
49
50

51 Q13. If we were to develop a larger study would your centre be prepared to participate?
52

- 53 i. Yes
54 ii. No
55

56 Q13a. If so please add contact details here or email Simon Leeson
57
58
59
60



Gynaecological cancer follow-up: National survey of current practice in the UK

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Gynaecological cancer follow-up national survey of current practice

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Abstract

Objective

To establish a baseline of national practice for follow-up after treatment for gynaecological cancer.

Design

Questionnaire survey.

Setting

Gynaecological cancer centres and units.

Geographical location

UK

Participants

Members of the British Gynaecological Cancer Society and the National Forum of Gynaecological Oncology Nurses.

Interventions

A questionnaire survey.

Outcome measures

To determine schedules of follow-up, who provides it and what routine testing is used for patients who have had previous gynaecological cancer.

Results

A total of 117 responses were obtained; 115 (98%) reported hospital scheduled regular follow-up appointments. Two involved General Practitioners. Follow-up was augmented or replaced by telephone follow-up in 29 (25%) and patient initiated appointments in 38 responses (32%). A total of 80 (68%) cancer specialists also offered combined follow-up clinics with other specialties. Clinical examinations for hospital based follow-up were mainly performed by doctors (67% for scheduled regular appointments and 63% for patient initiated appointments) while telephone follow-up was provided in the majority by nurses (76%). Most respondents provided routine tests (76/117 (65%)), from which 66/76 (87%) reported carrying out surveillance tests for ovarian cancer, 35/76 (46%) for cervical cancer, 8/76 (11%) for vulval cancer and 7/76 (9%) for endometrial cancer. Usually patients were discharged after five years (82/117 (70%)), whereas three (3%) were discharged after four years, nine (8%) after three and one (1%) after two years.

Conclusions

Practice varied but most used a standard hospital based protocol of appointments for five years and routine tests were performed usually for women with ovarian cancer. A minority utilised nurse led or telephone follow-up. General Practitioners were rarely involved in routine care. A randomised study comparing various models of follow-up could be considered.

273 words

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Article summary

Article focus

- Follow-up after treatment for cancer is a resource intense area of clinical practice which does not have clear benefits for patients.
- Doctors and nurses involved in care for women with gynaecological cancer were invited to respond to a questionnaire survey.
- A survey is presented of current follow-up after treatment for gynaecological cancer in the UK.

Key messages

- There is a variation of follow-up practice throughout the UK.
- A minority used nurse led or telephone follow-up as opposed to a conventional series of hospital outpatient appointments to see a doctor.

Strengths and limitations of this study

- A strength is that this is the first study to report the extent of patient initiated, specialist nurse or telephone follow-up for gynaecological cancer in the UK.
- A limitation is that four UK cancer networks did not respond.

Data sharing statement

The raw data has been archived at NWOORTH Clinical Trials Unit and will be available to interested researchers by agreement with the Principal Investigator.

Introduction

Traditionally, patients who have had treatment for cancer are kept on regular review in hospital out-patient clinics for a period of between five to 10 years after completion of their treatment. The aims may be to detect recurrence of tumour, to monitor late effects of treatment, to collect data and to offer patients an opportunity to raise concerns or anxieties arising from their cancer. The assumption behind this approach is that early detection of recurrence will be of benefit to patients and that monitoring side-effects and anxieties will allow helpful interventions that will improve quality of life.

Routine follow-up is a time-consuming and expensive process with many hundreds of patients attending clinics in each hospital each year at an NHS tariff of £118 per visit (Department of Health, 2011). In Wales alone we estimate the cost of this follow up is in excess of £1m annually. If the object is the early detection of recurrent disease, studies investigating recurrence for breast cancer reported most recurrences presenting between scheduled clinic appointments (Brøyn and Frøyen, 1982; Grunfeld *et al*, 1996; Pandya *et al*, 1985; Scanlon *et al*, 1980; Winchester *et al*, 1979; Zwaveling *et al*, 1987) and gynaecological patients may wait for their next routine appointment to disclose their symptoms (Olaitan *et al*, 2001). There is no prospective randomised evidence to suggest follow-up improves survival for ovarian cancer and retrospective data only to guide follow-up strategies for cervical cancer (Kew *et al*, 2011; Elit *et al*, 2009). Also there is no evidence that intensive follow up improves survival for endometrial cancer (Agboola *et al*, 1997; Allsop *et al*, 1997; Gadducci *et al*, 2000; Owen and Duncan, 1996; Reddoch *et al*, 1995; Salvesen *et al*, 1997; Shumsky *et al*, 1994). A cost benefit analysis for endometrial carcinoma showed that one asymptomatic recurrence was detected in every 653 consultations (Salvesen *et al*, 1997). In a review of 12 studies, only 30% of endometrial cancer recurrences were asymptomatic and methods of follow-up were unrelated to survival (Fung-Kee-Fung *et al*, 2006). As around 20% of all female cancer survivors have had gynaecological malignancy a cost effective form of surveillance is important (Salani *et al*, 2011).

In clinical practice there appears to be no rationale available for any particular follow-up protocol (Sartori *et al*, 2010). Rapid access to oncological assessment at recurrence may be more important than offering frequent routine appointments. Given that patients wish to be cured of their disease and that different schedules of follow-up do not appear to have an impact upon survival, delegation of routine follow-up could be to other carers. Telephone consultations can free oncologists' clinic time and is convenient for patients. Follow-up may be in primary care, a hospital based nurse led clinic, by telephone or at the request of the patient. Despite its place in standard healthcare the benefits of routine follow-up following treatment for gynaecological cancer has received little scrutiny and has rarely been subjected to formal assessment.

In order to determine a baseline of current practice for gynaecological cancer follow-up in the United Kingdom, we have performed a survey of cancer follow-up in gynaecological oncology. The intention is to investigate who performs follow-up, for what duration and how this is achieved to see if there is a possibility to improve the quality of care offered to patients after their cancer treatment.

Materials and methods

The follow-up survey was designed using the Bristol Online Survey (BOS) to provide electronic data capture and data management support to the questionnaire. The BOS is an easy-to-use survey tool, which allows developing, deploying and analysing surveys via the internet. The dataset was managed by the Information Systems Department at the North Wales Organisation of Randomised Trials (Bangor University). Data was anonymised and then exported to the databases held in SPSS™ (version 18.0; SPSS, Chicago, IL). The e-survey targeted gynaecological cancer secondary care practitioners (incorporating surgical and non-surgical specialists) in all cancer networks in the United Kingdom. It was available online using an electronic web link from June to September 2012. An initial invitation email and a reminder with the web link were sent through the Principal Investigator (PI) distribution list to all 401 members of the British Gynaecological Cancer Society (BGCS) and all 71 members of the National Forum of Gynaecological Oncology Nurses (NFGON). A news release published in June 2012 on the BGCS website also invited members to take part in the survey. It is possible that respondents could provide multiple replies but no two responses from the same network were identical.

The investigators in consultation with the BGCS and a patient representative designed the questionnaire which was organised around three themes (see questionnaire in appendix). The first comprised questions related to practice setting (i.e. organisation and hospital) and respondent characteristics (i.e. profession and medical specialty). The second comprised questions related to the use of standard protocols for follow-up. The bulk of the questionnaire addressed information about the different schedules of follow-up and which surveillance tests were used routinely in follow-up practices for different type of cancers. We listed four possible types of follow-up appointments; clinician led (traditional), nurse led, telephone follow-up and patient initiated follow-up. Telephone follow-up appointments were defined as a pre-arrangement for a member of the cancer team to contact the patient by telephone without a need for the patient to attend hospital. Patient initiated follow-up was defined as practice where the patient is not followed-up in secondary care but seen only if the patient requests or initiates a contact, for example if they are worried about a suspicion of recurrent disease.

Most answers were recorded as a binary variable (yes/no answer) with additional, open text box response options throughout the questionnaire for comments and alternative suggestions.

Data was collated and presented as numbers and a percentage of positive responses. For those questions composed of a subset of questions, the number of positive responses in the main question was used as the denominator for the subset. The geographical spread of responses was mapped. Textual answers were categorised and counted.

Results

Sample size and respondents characteristics

Responses were received from 118 experts in gynaecological cancer drawn from the membership of the BGCS and NFGON. Because the survey was conducted online with the request to take part

distributed widely by email it is impossible to state how many had the opportunity to take part but did not. Therefore the response rate has not been calculated. Nonetheless we received responses from 86% (24/28) of the cancer networks in England and all cancer networks in Scotland (three), Wales (two), and Northern Ireland (one). Each responding cancer network provided between one to 14 responses. One response was received from a surgical oncologist based in Greece who has been excluded from the study as the objective is assessing current practice of follow-up after gynaecological cancer treatment in the UK. Of the 117 respondents included in the study, 71 (61%) worked in a cancer centre, 32 (27%) in a cancer unit and 12 (10%) reported working in both. Eighty-eight (75%) of the respondents were surgical oncologists. Fifteen (13%) were clinical oncologists and six (5%) were specialised in medical oncology. The majority of the respondents (83 (71%)) were doctors while nurses constituted less than a third of the sample (32 (27%)). Full results are presented in table 1.

Standard follow-up protocols

All respondents with the exception of one surgical oncologist (116/117 (99%)) had a standard follow-up protocol after completion of treatment. However all 30 networks providing responses had at least one respondent reporting having protocols for follow-up. The vast majority of respondents provided follow-up in secondary care, only two respondents (from different English cancer networks) reported that visits to primary care are part of their follow-up routine.

Most 87/116 (75%) of the respondents reported using different follow-up protocols for different tumour sites (eg. cervix and ovary) and 35/116 (30%) reported having different protocols for different tumour types (eg. well or poorly differentiated). On a cancer network basis, different protocols for different tumour sites were reported from 29/30 (97%) networks. Different protocols for different tumour types were reported by respondents from 17/30 (57%) networks..

Composition follow-up appointments

All respondents in our sample reported they follow-up patients after completion of gynaecological cancer treatment. One hundred and fifteen (98%) reported hospital scheduled regular follow-up appointments from which the patient may be discharged if she remains disease free after a specified period of time. This follow-up was augmented or replaced by a telephone follow-up in 29 (25%) and patient initiated appointments in 38 responses (32%). A combination of all three forms of follow-up was reported by 11 respondents (a total of 54 respondents offered more than one modality of follow-up). Of these 18/54 (33%) reported that patients have an opportunity to attend either a medical or a nurse led clinic. However, 6/18 (33%) did not have a protocol to allocate patients to each clinic. For patient initiated appointments, 10/38 (26%) did not have a protocol with contact details (eg. a secretary, Macmillan nurse or General Practitioner) for self-referrals. A total of 80/117 (68%) cancer specialists from 27/30 networks (90%) also offered combined follow-up clinics with other specialties (eg. combined surgical and medical oncology or surgical and clinical oncology clinics).

Virtually all respondents reported in the case of sudden events that symptomatic patients could arrange an appointment in less than two weeks. Seven (6%) respondents from five different cancer networks answered that their practices schedule urgent appointments in a period of two to four

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3 weeks, from which two of them also scheduled urgent patient initiated appointments in the same
4 timeframe.
5

6 Follow-up in hospital was mainly performed by doctors (67% for scheduled regular appointments and
7 63% for patient initiated appointments) while telephone follow-up care was provided in its majority by
8 nurses (76%). Full details are illustrated in table 2.
9

10 11 12 13 ***Duration of follow-up and surveillance tests***

14 The survey asked respondents whether they perform any type of routine surveillance test during
15 follow-up. Routine tests were requested by 65% (76/117) of respondents, from which 87% (66/76)
16 requested tests for ovarian cancer, 46% (35/76) for cervical cancer, 11% (8/76) for vulva cancer and
17 nine per cent (7/76) for endometrial cancer. In addition, respondents were asked to provide details of
18 when these tests are performed but only a few responses were obtained. Table 3 shows the
19 distribution of the different type of tests employed during follow-up.
20
21

22 CA125 measurement was the most frequently used test (60/66 (91%)) during follow-up of ovarian
23 cancer patients. Other blood tests (8/66 (12%)), eg. alpha-fetoprotein , carcino-embryonic antigen ,
24 CA19.9 and inhibin were also requested. The routine use of computed tomography and magnetic
25 resonance imaging (MRI) scans for ovarian cancer were reported by 9/66 (14%) of the respondents
26 (one respondent used both CT and MRI). Eight respondents stated the CA125 test is performed at each
27 visit. Another seven reported the CA125 is performed every three months for the first year after
28 completion of treatment, from which two reported they carry on with routine testing for the second
29 year and four up to the fifth year every six months.
30
31

32 The use of MRI (15/35 (43%)) was the most common investigation employed in the follow-up of
33 cervical cancer with cervical or vaginal cytology being the second commonest method (14/35 (40%)).
34 There was a wide variety of tests (8/35 (23%)) reported in the follow-up of this type of cancer. Two of
35 the respondents stated they perform vault cytology for cervical cancer patients annually for a period
36 of five years following hysterectomy, while three specialists reported carrying out the test at six and
37 18 months post-treatment.
38
39

40 Most respondents discharged their patients after five years of follow-up (82/117 (70%)), three (3%)
41 after four years, nine (8%) after three and one (1%) after two years whereas 22/117 (19%) of
42 respondents did not answer this question.
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45

46 47 48 **Discussion**

49 The current survey is the first evidence reporting the extent of patient initiated, specialist nurse or
50 telephone follow-up for gynaecological cancer in the UK. There were no respondents for four cancer
51 networks and because the survey was online, a response rate could not be calculated. This could
52 introduce a potential source of bias if the answers from respondents were not representative of their
53 relevant professional communities. Different protocols for different tumour sites and types and the
54 use of combined speciality follow-up clinics were more often reported from network responses than
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3 for individual responses because network responses included respondents with at least one positive
4 response in each network. Unfortunately we could not calculate the agreement level within networks
5 because of the small numbers of respondents from each network. The lack of consistency of responses
6 within networks is again a potential source of error. Our survey shows that all gynaecological cancer
7 networks providing responses have protocols for follow-up after treatment. Follow-up for patients
8 treated for gynaecological cancer is mainly performed by doctors in secondary care. Patient initiated
9 follow-up was offered by 32% of respondents and telephone follow-up was offered by 25%. A large
10 minority of patient initiated follow-up and combined follow-up schedules did not have protocols to
11 guide practice. The most common duration of routine follow-up was for five years. There are few
12 routine tests undertaken during follow-up to detect recurrence and they show no consistency
13 particularly for cervical cancer. Of the 35 respondents who requested tests for cervical cancer follow-
14 up, 15 (43%) requested MRI and 14 (40%) requested cytology. Such variation is not surprising with the
15 lack of evidence to guide clinical management. The exception is CA125 testing following treatment for
16 ovarian cancer where 52% of all respondents recommended CA125 monitoring despite grade one
17 evidence to demonstrate that routine CA125 measurements do not benefit asymptomatic patients
18 having had ovarian cancer (Rustin *et al*, 2010). Furthermore, there appears to have been no recent
19 change of this practice in our survey, as monitoring with CA125 testing was reported in 24 of the 34
20 UK networks (71%) whereas 67% of networks recommended such testing in an earlier survey (Kew and
21 Cruickshank, 2006). Respondents were asked not to include tests requested during treatment but tests
22 could have been included as part of trial protocols.

23
24 Vistad *et al* (2012) also published results of a web-based survey of practice amongst gynaecological
25 oncologists across Europe and reported that 47% of the 375 respondents considered follow-up with
26 General Practitioners to be acceptable. Other options for care were not considered and the response
27 rate was thought to be below 20%. However there appears to be little or no evidence upon which to
28 guide follow-up for gynaecological malignancy from the survey by Vistad *et al*, the earlier survey from
29 the UK (Kew and Cruickshank, 2006) and from our work.

30
31 From other research, patients with previous ovarian cancer rated CA125 testing as the most important
32 part of follow-up (Kew *et al*, 2009) despite a lack of evidence of benefit from routine measurement of
33 the CA125 value upon survival (Rustin *et al*, 2010). Furthermore knowledge of recurrence whether
34 treatable or not appears useful to patients (Papagrigoriadis and Heyman, 2003) and information
35 should be provided to detail the scope and limitations of follow-up (Kew *et al*, 2007). Rapid access to
36 oncological assessment at recurrence may be more important than offering frequent routine
37 appointments. Given that patients wish to be cured of their disease and knowing that different
38 schedules of follow-up do not have an impact upon survival, delegation of routine follow-up could be
39 to other carers (Vistad *et al*, 2012). Follow-up may be in primary care, a hospital based nurse led clinic,
40 by telephone or at the request of the patient. An individualised approach to follow-up is likely to be
41 important to concentrate care for those perceived to be at a greater risk of recurrent disease or other
42 issues of survivorship. This may include a risk stratification where there are effective interventions for
43 physical, psychological and social issues as well as needs assessments which are clearly patient centred
44 as defined by the National Cancer Survivorship Initiative (Watson *et al*, 2012) whilst bearing in mind
45 that a minority of patients may be cured with further therapy. Follow-up has to be multidisciplinary,
46 designed for risk of recurrence and with good communication between professional groups. Informed
47 patient choice regarding mode and frequency of follow-up is important. Reducing the frequency of
48 follow-up appointments may not place an increased demand upon unnecessary patient initiated extra
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3 hospital appointments and patients may prefer fewer appointments (Gulliford *et al*, 1997). The ideal
4 time of advising a patient about a preferred form of follow-up is unclear but may be shortly after all
5 modalities of treatment have been completed.
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8 Healthcare providers should be informed by prospective data on the validity of alternative strategies
9 for gynaecological cancer follow-up which is already a minority part of current UK practice. The North
10 Wales Organisation for Randomised Trials in Health in collaboration with several leading
11 gynaecological oncologists has previously developed a proposal for a randomised study to assess the
12 value of hospital follow-up of endometrial cancer (Follow-up in Gynaecological Cancer Units: RCT for
13 Endometrium or FIGURE). The proposal was for a multicentre, randomised trial comparing standard
14 (hospital) follow-up with patient initiated review. The endpoints were to be quality of life and survival
15 with a planned recruitment of 2200 patients to detect an effect size of 0.2. Unfortunately, although
16 the proposal was well received, it was impossible to agree a level of funding to allow the study to
17 proceed. More recently the Endometrial Cancer Telephone Follow-up Trial (ENDCAT ISRCTN
18 75220876) has started. This is a study comparing traditional hospital follow-up with telephone follow-
19 up by specialist gynaecology oncology nurses with primary outcomes of psychological morbidity and
20 patient satisfaction. Again this is a randomised trial for endometrial cancers only and is at a single
21 centre. It is currently recruiting to schedule and is due to close in 2014. A Trial between Two Follow-up
22 Regimens with Different Intensity in Endometrial Cancer Treated Patients (TOTEM NCT00916708) is a
23 further ongoing but multicentre randomised trial in Italy, comparing overall survival, progression free
24 survival, complications, proportion of asymptomatic relapse and the proportion of patients completing
25 each regimen for follow-up. It is due to close in 2015.
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31 Our study has demonstrated that the vast majority of follow-up still reflects traditional patterns, with
32 only about a third of practitioners incorporating more flexible follow-up routines. However, the
33 evidence base for changing practice to a less intensive follow-up programme for gynaecological cancer
34 is poor and Vistad *et al* (2011) reported no randomised studies on this subject. A trial similar to FIGURE
35 should be revisited but to include follow-up for more than one gynaecological cancer site. In the
36 present constrained financial environment, to continue to use patterns of follow-up for gynaecological
37 cancers which are neither evidence-based nor affordable is inappropriate. A multicentre randomised
38 controlled trial could assess the clinical benefits and costs of routine hospital follow-up in comparison
39 with the patient being empowered to choose her preferred format of follow-up for most
40 gynaecological cancers. The current survey may inform design of such a trial by providing data from
41 the UK concerning national practice.
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3150 words

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31 Authors' roles

32
33 Simon Leeson final manuscript preparation, review of data, design of questionnaire
34 Nick Stuart draft script development, design of questionnaire
35 Yvonne Sylvestre review of data
36 Liz Hall draft script development
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Table 1: Characteristics of respondents (N=117)

	N (%)
Region	
England	102 (87%)
Wales	7 (6%)
Scotland	5 (4%)
Northern Ireland	3 (3%)
Organisation	
Cancer centre	71 (61%)
Cancer unit	32 (27%)
Cancer unit & cancer centre	12 (10%)
Other ¹	2 (2%)
Specialty	
Surgical oncology	73 (62%)
Medical oncology	6 (5%)
Clinical oncology	15 (13%)
Surgical & medical oncology	6 (5%)
Surgical & clinical oncology	1 (1%)
Surgical, medical & clinical oncology	8 (7%)
Other ²	8 (7%)
Profession	
Medical	83 (71%)
Nursing	32 (27%)
Other ³	2 (2%)

1. Includes gynaecology unit in a chemotherapy centre (n=1) and hospital (n=1).

2. Includes clinical nurse specialist (n=2), nursing (n=2), gynaecology (n=2), gynaecology & surgical oncology (n=1) and pathology (n=1).

3. Includes consultant radiographer (n=1) and missing response (n=1).

Table 2: Type and frequency of occurrence of differing modes of follow-up

	Regular	Telephone	Patient initiated
Positive responses	115/117 (98%)	29/117 (25%)	38/117 (32%)
Urgent follow-up bookings			
< 2 weeks	108/115 (94%)	29/29 (100%)	35/38 (92%)
2 to 4 weeks	7/115 (6%)	0 (0%)	2/38 (5%)
Responsible for follow-up			
Doctors	77/115 (67%)	4/29 (14%)	24/38 (63%)
Nurses	0 (0%)	22/29 (76%)	2/38 (5%)
Doctors & nurses	36/115 (31%)	3/29 (10%)	11/38 (29%)
Other ¹	2/115 (2%)	1/29 (3%)	1/38 (3%)

1. Includes radiographer (n=1), consultant radiographer (n=1), for regular appointments; specialist radiographer (n=1) for telephone appointments and missing response (n=1) for patient initiated appointments.

Table 3: Frequency of surveillance tests reported by type of test and cancer type

	Ultrasound [†]	CA125	Other blood tests*	CT	MRI	Cytology	Other [¶]	Total
Ovarian	5	60	8	5	4	0	0	82
Cervical	1	0	4	0	15	14	3	37
Endometrial	1	1	0	0	1	1	0	4
Vulval	0	0	0	0	1	0	4	5

Key: CA125, cancer antigen 125; CT, computed tomography; MRI, magnetic resonance imaging.

[†] Ultrasound includes: abdominal and transvaginal ultrasound.

* Other blood tests includes: other tumour markers (n=8) for ovarian cancer and squamous cancer antigen (n=3) for cervical cancer.

[¶] Other includes: colposcopy (n=2) for cervical cancer and vulvoscopy (n=3) for vulval cancer.



Gynaecological cancer follow-up national survey of current practice

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Key words: neoplasm, questionnaires, female continuity of patient care/standards, survivorship, neoplasm recurrence



Abstract

Objective

To establish a baseline of national practice for follow-up after treatment for gynaecological cancer.

Design

Questionnaire survey.

Setting

Gynaecological cancer centres and units.

Geographical location

UK

Participants

Members of the British Gynaecological Cancer Society and the National Forum of Gynaecological Oncology Nurses.

Interventions

A questionnaire survey ~~was circulated to enquiring about schedules of follow up, who provides it and what routine testing is used.~~

Outcome measures

~~To determine schedules of follow-up, who provides it and what routine testing is used~~~~To determine if follow-up could be modified to improve the survivorship experience~~ for patients who have had previous gynaecological cancer.

Results

A total of 117 responses were obtained; 115 (98%) reported hospital scheduled regular follow-up appointments. Two involved General Practitioners. Follow-up was augmented or replaced by telephone follow-up in 29 (25%) and patient initiated appointments in 38 responses (32%). A total of 80 (68%) cancer specialists also offered combined follow-up clinics with other specialties. Clinical examinations for hospital based follow-up ~~were~~ mainly performed by doctors (67% for scheduled regular appointments and 63% for patient initiated appointments) while telephone follow-up ~~care~~ ~~was~~ provided in the majority by nurses (76%). Most respondents provided ~~d~~ routine tests (76/117 (65%)), from which 66/76 (87%) reported carrying out surveillance tests for ovarian cancer, 35/76 (46%) for cervical cancer, 8/76 (11%) for vulval cancer and 7/76 (9%) for endometrial cancer. Usually patients were discharged after five years (82/117 (70%)), whereas three (3%) were discharged after four years, nine (8%) after three and one (1%) after two years.

Conclusions

Practice varied but most used a standard hospital based protocol of appointments for five years and routine tests were performed usually for women with ovarian cancer. A minority utilised nurse led or telephone follow-up. General Practitioners were rarely involved in routine care. A randomised study comparing various models of follow-up could be considered.

273 words

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12 **Article summary**

13 **Article focus**

- 14 • Follow-up after treatment for cancer is a resource intense area of clinical practice which does
15 not have clear benefits for patients.
- 16 • Doctors and nurses involved in care for women with gynaecological cancer were invited to
17 respond to a questionnaire survey.
- 18 • A survey is presented of current follow-up after treatment for gynaecological cancer in the UK.

19 **Key messages**

- 20 • There is a variation of follow-up practice throughout the UK.
- 21 • A minority used nurse led or telephone follow-up as opposed to a conventional series of
22 hospital outpatient appointments to see a doctor.

23 **Strengths and limitations of this study**

- 24 • A strength is that this is the first study to report the extent of patient initiated, specialist
25 nurse or telephone follow-up for gynaecological cancer in the UK.
- 26 • A limitation is that four UK cancer networks did not respond.

27 **Data sharing statement**

28 The raw data has been archived at NWORD Clinical Trials Unit and will be available to interested
29 researchers by agreement with the Principal Investigator.

Introduction

Traditionally, patients who have had treatment for cancer are kept on regular review in hospital out-patient clinics for a period of between five to 10 years after completion of their treatment. The aims may be to detect recurrence of tumour, to monitor late effects of treatment, to collect data and to offer patients an opportunity to raise concerns or anxieties arising from their cancer. The assumption behind this approach is that early detection of recurrence will be of benefit to ~~the patients~~ and that monitoring side-effects and anxieties will allow helpful interventions that will improve ~~the patient's~~ quality of life.

Routine follow-up is a time-consuming and expensive process with many hundreds of patients attending clinics in each hospital each year at an NHS tariff of £118 per visit (Department of Health, 2011). In Wales alone we estimate the cost of this follow up is in excess of £1m annually. If the object is the early detection of recurrent disease, studies investigating recurrence for breast cancer reported most recurrences presenting between scheduled clinic appointments (Brøyn and Frøyen, 1982; Grunfeld *et al*, 1996; Pandya *et al*, 1985; Scanlon *et al*, 1980; Winchester *et al*, 1979; Zwaveling *et al*, 1987) and gynaecological patients may wait for their next routine appointment to disclose their symptoms (Olaitan *et al*, 2001). There is no prospective randomised evidence to suggest follow-up improves survival for ovarian cancer and retrospective data only to guide follow-up strategies for cervical cancer (Kew *et al*, 2011; Elit *et al*, 2009). Also there is no evidence that intensive follow up improves survival for endometrial cancer (Agboola *et al*, 1997; Allsop *et al*, 1997; Gadducci *et al*, 2000; Owen and Duncan, 1996; Reddoch *et al*, 1995; Salvesen *et al*, 1997; Shumsky *et al*, 1994). A cost benefit analysis for endometrial carcinoma showed that one asymptomatic recurrence was detected in every 653 consultations (Salvesen *et al*, 1997). In a review of 12 studies, only 30% of endometrial cancer recurrences were asymptomatic and methods of follow-up were unrelated to survival (Fung-Kee-Fung *et al*, 2006). As around 20% of all female cancer survivors have had gynaecological malignancy a cost effective form of surveillance is important (Salani *et al*, 2011).

In clinical practice there appears to be no rationale available for any particular follow-up protocol (Sartori *et al*, 2010). Rapid access to oncological assessment at recurrence may be more important than offering frequent routine appointments. Given that patients wish to be cured of their disease and that different schedules of follow-up do not appear to have an impact upon survival, delegation of routine follow-up could be to other carers. Telephone consultations can free oncologists' clinic time and is convenient for patients. Follow-up may be in primary care, a hospital based nurse led clinic, by telephone or at the request of the patient. Despite its place in standard healthcare the benefits of routine follow-up following treatment for gynaecological cancer has received little scrutiny and has rarely been subjected to formal assessment.

In order to determine a baseline of current practice for gynaecological cancer follow-up in the United Kingdom, we have performed a survey of cancer follow-up in gynaecological oncology. The intention ~~aim~~ is to investigate who performs follow-up, for what duration and how this is achieved to see if there is a possibility to improve the quality of care offered to patients after their cancer treatment.

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Materials and methods

The follow-up survey was designed using the Bristol Online Survey (BOS) to provide electronic data capture and data management support to the questionnaire. The BOS is an easy-to-use survey tool, which allows developing, deploying and analysing surveys via the internet. The dataset was managed by the Information Systems Department at the North Wales Organisation of Randomised Trials (Bangor University). Data was anonymised and then exported to the databases held in SPSS™ (version 18.0; SPSS, Chicago, IL). The e-survey targeted gynaecological cancer [secondary care practitioner experts \(incorporating surgical and non-surgical specialists\)](#) in all cancer networks in the United Kingdom. It was available online using an electronic web link from June to September 2012. An initial invitation email and a reminder with the web link were sent through the Principal Investigator (PI) distribution list [to all 401 members](#) of the British Gynaecological Cancer Society (BGCS) and [all 71 members of the](#) National Forum of Gynaecological Oncology Nurses (NFGON). A news release published in June 2012 on the BGCS website also invited members to take part in the survey. [It is possible that respondents could provide multiple replies but no two responses from the same network were identical.](#)

The investigators in consultation with the BGCS and a patient representative designed the questionnaire which was organised around three themes (see questionnaire in appendix). The first comprised questions related to practice setting (i.e. organisation and hospital) and respondent characteristics (i.e. profession and medical specialty). The second comprised questions related to the use of standard protocols for follow-up. The bulk of the questionnaire addressed information about the different schedules of follow-up and which surveillance tests were used routinely in follow-up practices for different type of cancers. We listed four possible types of follow-up appointments; clinician led (traditional), nurse led, telephone follow-up and patient initiated follow-up. Telephone follow-up appointments were defined as a pre-arrangement for a member of the cancer team to contact the patient by telephone without a need for the patient to attend hospital. Patient initiated follow-up was defined as practice where the patient is not followed-up in secondary care but seen only if the patient requests or initiates a contact, for example if they are worried about a suspicion of recurrent disease.

Most answers were recorded as a binary variable (yes/no answer) with additional, open text box response options throughout the questionnaire for comments and alternative suggestions.

Data was collated and presented as numbers and a percentage of [positive responses. For those questions composed of a subset of questions, the number of positive responses in the main question was used as the denominator for the subset applicable denominators.](#) The geographical spread of responses was mapped. Textual answers were categorised and counted.

Results

Sample size and respondents characteristics

Responses were received from 118 experts in gynaecological cancer drawn from the membership of the BGCS and NFGON. Because the survey was conducted online with the request to take part distributed widely by email it is impossible to state how many had the opportunity to take part but did not. Therefore the response rate has not been calculated. Nonetheless we received responses from 86% (24/28) of the cancer networks in England and all cancer networks in Scotland (three), Wales (two), ~~Scotland (three)~~ and Northern Ireland (one). Each responding cancer network provided between one to 14 responses. One response was received from a surgical oncologist based in Greece who has been excluded from the study as the objective is assessing current practice of follow-up after gynaecological cancer treatment in the UK. Of the 117 ~~respondent~~cancer specialists included in the study, 71 (61%) worked in a cancer centre, 32 (27%) in a cancer unit and 12 (10%) reported working in both. Eighty-eight (75%) of the respondents were surgical oncologists. Fifteen (13%) were clinical oncologists and six (5%) were specialised in medical oncology. The majority of the respondents (83 (71%)) were doctors while nurses constituted less than a third of the sample (32 (27%)). Full results are presented in table 1.

Standard follow-up protocols

All respondents with the exception of one surgical oncologist (116/117 (99%)) ~~reported that they~~ had a standard follow-up protocol after completion of treatment. However all 30 networks providing responses had at least one respondent reporting having protocols for follow-up. The vast majority of respondents provided follow-up in secondary care, only two respondents (from different English cancer networks) reported that visits to primary care are part of their follow-up routine.

Most 87/116 (75%) of the respondents reported using different follow-up protocols for different tumour sites (eg. cervix and ovary) and 35/116 (30%) reported having ~~a~~ different protocols for different tumour types (eg. well or poorly differentiated). On a cancer network basis, different identical protocols for different tumour sites were reported ~~from in~~ 29/46/30 (97%) networks. ~~Different identical~~ protocols for different tumour types were reported by respondents from 172/30 (57%) ~~3 of the 24 English networks, both of the Wales networks, the Northern Ireland network, and one of the cancer networks in Scotland.~~

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Composition follow-up appointments

All respondents in our sample reported they follow-up patients after completion of gynaecological cancer treatment. One hundred and fifteen (98%) reported hospital scheduled regular follow-up appointments from which the patient may be discharged if she remains disease free after a specified period of time. This follow-up was augmented or replaced by a telephone follow-up in 29 (25%) and patient initiated appointments in 38 responses (32%). A combination of all three forms of follow-up was reported by 11 respondents (a total of 54 respondents offered more than one modality of follow-up). ~~regular, telephone or patient initiated follow-up was available from 33 respondents and~~ Of these 189/54 (33%) (58%) reported ~~that~~ patients have an opportunity to attend either a medical or a nurse led clinic. However, 6/189 (3.2%) did not have a protocol to allocate patients to each clinic. For patient initiated appointments, 10/38 (26%) ~~of the specialists~~ did not have a protocol with contact

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7 details (eg. a secretary, Macmillan nurse or General Practitioner) for self-referrals. A total of 808/117
8 (68%) cancer specialists ~~from 27/30 networks (90%)~~ also offered combined follow-up clinics with other
9 specialties (eg. combined surgical and medical oncology or surgical and clinical oncology clinics).

10
11 Virtually all respondents reported in the case of sudden events that symptomatic patients could
12 arrange an appointment in less than two weeks. Seven (6%) respondents from five different cancer
13 networks answered that their practices schedule urgent appointments in a period of two to four
14 weeks, from which two of them also scheduled urgent patient initiated appointments in the same
15 timeframe.

16
17 Follow-up in hospital ~~was~~ mainly performed by doctors (67% for scheduled regular appointments and
18 63% for patient initiated appointments) while telephone follow-up care ~~was~~ provided in its majority
19 by nurses (76%). Full details are illustrated in table 2.

20 21 22 **Duration of follow-up and surveillance tests** 23

24 The survey asked respondents whether they perform any type of routine ~~follow-up or~~ surveillance test
25 during follow-up. Routine tests ~~were~~ ~~are~~ ~~requested~~ ~~provided~~ by 65% (76/117) of respondents, from
26 which 87% (66/76) ~~requested~~ ~~reported~~ ~~carrying out~~ tests for ovarian cancer, 46% (35/76) for cervical
27 cancer, 11% (8/76) for vulva cancer and nine per cent (7/76) for endometrial cancer. In addition,
28 respondents were asked to provide details of when these tests are performed but only a few
29 responses were obtained. Table 3 shows the distribution of the different type of tests employed
30 during follow-up.

31
32 CA125 measurement was the most frequently used test (60/66 (91%)) during follow-up of ovarian
33 cancer patients. ~~O~~ ~~followed by~~ other blood tests (8/66 (12%)), eg. alpha-fetoprotein , carcino-
34 embryonic antigen , CA19.9 and inhibin ~~were also requested~~. The routine use of computed
35 tomography and magnetic resonance imaging (MRI) scans for ovarian cancer were reported by 9/66
36 (14%) of the respondents (one respondent used both CT and MRI). Eight ~~respondents~~ ~~cancer specialists~~
37 stated the CA125 test is performed at each visit. Another seven ~~specialists~~ reported the CA125 is
38 performed every three months for the first year after completion of treatment, from which two ~~of~~
39 ~~them~~ reported they carry on with routine testing for the second year and four up to ~~the fifth year~~ ~~five~~
40 every six months.

41
42 The use of MRI (15/35 (43%)) was the most common investigation employed in the follow-up of
43 cervical cancer with cervical or vaginal cytology being the second commonest method (14/35 (40%)).
44 There was a wide variety of tests (8/35 (23%)) reported in the follow-up of this type of cancer. Two of
45 the respondents stated they perform vault cytology for cervical cancer patients annually for a period
46 of five years following hysterectomy, while three specialists reported carrying out the test at six and
47 18 months post-treatment.

48
49 Most respondents discharged their patients after five years of follow-up (82/117 (70%)), three (3%)
50 after four years, nine (8%) after three and one (1%) after two years whereas 22/117 (19%) of
51 respondents did not answer this question.
52

Discussion

The current survey is the first evidence reporting the extent of patient initiated, specialist nurse or telephone follow-up for gynaecological cancer in the UK. There were no respondents for four cancer networks and because the survey was online, a response rate could not be calculated. This could introduce a potential source of bias if the answers from respondents were not representative of their relevant professional communities. Different protocols for different tumour sites and types and the use of combined speciality follow-up clinics were more often reported from network responses than for individual responses because network responses included respondents with at least one positive response in each network. Unfortunately we could not calculate the agreement level within networks because of the small numbers of respondents from each network. The lack of consistency of responses within networks is again a potential source of error. Our survey ~~also~~ shows that all gynaecological cancer networks providing responses have protocols for follow-up after treatment. Follow-up for patients treated for gynaecological cancer is mainly performed by doctors in secondary care. Patient initiated follow-up was offered by 32% of respondents and telephone follow-up was offered by 25%. A large minority of patient initiated follow-up and combined follow-up schedules did not have protocols to guide practice. The most common duration of routine follow-up was for five years. There are few routine tests undertaken during follow-up to detect recurrence and they show no consistency particularly for cervical cancer. Of the 35 respondents who requested tests for cervical cancer follow-up, 15 (43%) requested MRI and 14 (40%) requested cytology. Such variation is not surprising with the lack of evidence to guide clinical management. The exception is CA125 testing following treatment for ovarian cancer where 52% of all respondents recommended CA125 monitoring despite grade one evidence to demonstrate that routine CA125 measurements do not benefit asymptomatic patients having had ovarian cancer (Rustin *et al*, 2010). Furthermore, there appears to have been no recent change of this practice in our survey, as monitoring with CA125 testing was reported in 24 of the 34 UK networks (71%) whereas 67% of networks recommended such testing in an earlier survey (Kew and Cruickshank, 2006). Respondents were asked not to include tests requested during treatment but tests could have been included as part of trial protocols. Patient initiated follow up was offered by 32% of respondents and telephone follow up was offered by 25%. A large minority of patient initiated follow up and combined follow up schedules did not have protocols to guide practice. The most common duration of routine follow up is for five years.

Vistad *et al* (2012) also published results of a web-based survey of practice amongst gynaecological oncologists across Europe and reported that 47% of the 375 respondents considered follow-up with General Practitioners to be acceptable. Other options for care were not considered and the response rate was thought to be below 20%. However there appears to be little or no evidence upon which to guide follow-up for gynaecological malignancy from the survey by Vistad *et al*, the earlier survey from the UK (Kew and Cruickshank, 2006) and from our work.

From other research, patients with previous ovarian cancer rated CA125 testing as the most important part of follow-up (Kew *et al*, 2009) despite a lack of evidence of benefit from routine measurement of despite the knowledge that routinely measuring the CA125 value upon does not improve survival (Rustin *et al*, 2010). Furthermore knowledge of recurrence whether treatable or not appears useful to patients (Papagrigoriadis and Heyman, 2003) (Kew *et al*, 2009) and information should be provided to detail the scope and limitations of follow-up (Kew *et al*, 2007). Rapid access to oncological assessment at recurrence may be more important than offering frequent routine appointments. Given that

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7 patients wish to be cured of their disease and knowing that different schedules of follow-up do not
8 have an impact upon survival, delegation of routine follow-up could be to other carers (Vistad *et al*,
9 2012). Follow-up may be in primary care, a hospital based nurse led clinic, by telephone or at the
10 request of the patient. An individualised approach to follow-up is likely to be important to concentrate
11 care for those perceived to be at a greater risk of recurrent disease or other issues of survivorship. This
12 may include a risk stratification assessment where there are effective interventions for physical,
13 psychological and social issues as well as needs assessments which are clearly patient centred as
14 defined by the National Cancer Survivorship Initiative (Watson *et al*, 2012) whilst bearing in mind that
15 a minority of patients may be cured with further therapy. Follow-up has to be multidisciplinary,
16 designed for risk of recurrence and with good communication between professional groups. Informed
17 patient choice regarding mode and frequency of follow-up is important. Reducing the frequency of
18 follow-up appointments may not place an increased demand upon unnecessary patient initiated extra
19 hospital appointments and patients may prefer fewer appointments (Gulliford *et al*, 1997). The ideal
20 time of advising a patient about a preferred form of follow-up is unclear but may be shortly after all
21 modalities of treatment have been completed.
22

23
24 Healthcare providers should be informed by prospective data on the validity of alternative strategies
25 for gynaecological cancer follow-up which is already a minority part of current UK practice. The North
26 Wales Organisation for Randomised Trials in Health in collaboration with several leading
27 gynaecological oncologists has previously developed a proposal for a randomised study to assess the
28 value of hospital follow-up of endometrial cancer (Follow-up in Gynaecological Cancer Units: RCT for
29 Endometrium or FIGURE). The proposal was for a multicentre, randomised trial comparing standard
30 (hospital) follow-up with patient initiated review. The endpoints were to be quality of life and survival
31 with a planned recruitment of 2200 patients to detect an effect size of 0.2. Unfortunately, although
32 the proposal was well received, it was impossible to agree a level of funding to allow the study to
33 proceed. More recently the Endometrial Cancer Telephone Follow-up Trial (ENDCAT ISRCTN
34 75220876) has started. This is a study comparing traditional hospital follow-up with telephone follow-
35 up by specialist gynaecology oncology nurses with primary outcomes of psychological morbidity and
36 patient satisfaction. Again this is a randomised trial for endometrial cancers only and is at a single
37 centre. It is currently recruiting to schedule and is due to close in 2014. A Trial between Two Follow-up
38 Regimens with Different Intensity in Endometrial Cancer Treated Patients (TOTEM NCT00916708) is a
39 further ongoing but multicentre randomised trial in Italy, comparing overall survival, progression free
40 survival, complications, proportion of asymptomatic relapse and the proportion of patients completing
41 each regimen for follow-up. It is due to close in 2015.
42

43
44 Our study has demonstrated that the vast majority of follow-up still reflects traditional patterns, with
45 only about a third of practitioners incorporating more flexible follow-up routines. However, the
46 evidence base for changing practice to a less intensive follow-up programme for gynaecological cancer
47 is poor and Vistad *et al* (2011) reported no randomised studies on this subject. A ~~Current trial activity~~
48 ~~suggests a trial similar to FIGURE should be revisited but to include follow-up for more than one~~
49 ~~gynaecological cancer site. Practice has already begun to change to include patient initiated follow-up~~
50 ~~for gynaecological cancer patients but our survey has demonstrated that these changes are not yet~~
51 ~~widespread. However, the evidence base for changing practice to a less intensive follow-up~~
52 ~~programme for gynaecological cancer is poor and Vistad *et al* (2011) reported no randomised studies~~
53 ~~on this subject. The current scoping study has demonstrated that the vast majority of follow-up still~~
54 ~~reflects traditional patterns, with only about a third of practitioners incorporating more flexible follow-~~
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~~up routines into their practice.~~ In ~~the our present current~~ constrained financial environment, to continue to use patterns of follow-up for gynaecological cancers which are neither evidence-based nor affordable is inappropriate. ~~We aim to develop a suite of pilot and feasibility studies that may lead to a UK A~~ multicentre randomised controlled trial ~~could to~~ assess the clinical benefits and costs of routine hospital follow-up in comparison with the patient being empowered to choose her preferred format of follow-up for most gynaecological cancers. ~~This would incorporate information with contact details and about the possible symptoms of recurrence, with formal review only as and when required by the patient.~~ The current survey ~~may inform design of such a trial by providing data from the UK is the first in this series concerning~~ ~~in assessing current~~ national practice.

3150 words

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30 Authors' roles

31
32 Simon Leeson final manuscript preparation, review of data, design of questionnaire
33 Nick Stuart draft script development, design of questionnaire
34 Yvonne Sylvestre review of data
35 Liz Hall draft script development
36 Rhiannon Whitaker draft script development, review of data, design of questionnaire
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Table 1: Characteristics of respondents (N=117)

	N (%)
Region	
England	102 (87%)
Wales	7 (6%)
Scotland	5 (4%)
Northern Ireland	3 (3%)
Organisation	
Cancer centre	71 (61%)
Cancer unit	32 (27%)
Cancer unit & cancer centre	12 (10%)
Other ¹	2 (2%)
Specialty	
Surgical oncology	73 (62%)
Medical oncology	6 (5%)
Clinical oncology	15 (13%)
Surgical & medical oncology	6 (5%)
Surgical & clinical oncology	1 (1%)
Surgical, medical & clinical oncology	8 (7%)
Other ²	8 (7%)
Profession	
Medical	83 (71%)
Nursing	32 (27%)
Other ³	2 (2%)

1. Includes gynaecology unit in a chemotherapy centre (n=1) and hospital (n=1).

2. Includes clinical nurse specialist (n=2), nursing (n=2), gynaecology (n=2), gynaecology & surgical oncology (n=1) and pathology (n=1).

3. Includes consultant radiographer (n=1) and missing response (n=1).

Table 2: Type and frequency of occurrence of differing modes of follow-up

	Regular	Telephone	Patient initiated
Positive responses	115/117 (98%)	29/117 (25%)	38/117 (32%)
Urgent follow-up bookings			
< 2 weeks	108/115 (94%)	29/29 (100%)	35/38 (92%)
2 to 4 weeks	7/115 (6%)	0 (0%)	2/38 (5%)
Responsible for follow-up			
Doctors	77/115 (67%)	4/29 (14%)	24/38 (63%)
Nurses	0 (0%)	22/29 (76%)	2/38 (5%)
Doctors & nurses	36/115 (31%)	3/29 (10%)	11/38 (29%)
Other ¹	2/115 (2%)	1/29 (3%)	1/38 (3%)

1. Includes radiographer (n=1), consultant radiographer (n=1), for regular appointments; specialist radiographer (n=1) for telephone appointments and missing response (n=1) for patient initiated appointments.

Table 3: Frequency of surveillance tests reported by type of test and cancer type

	Ultrasound [†]	CA125	Other blood tests*	CT	MRI	Cytology	Other [¶]	Total
Ovarian	5	60	8	5	4	0	0	82
Cervical	1	0	4	0	15	14	3	37
Endometrial	1	1	0	0	1	1	0	4
Vulval	0	0	0	0	1	0	4	5

Key: CA125, cancer antigen 125; CT, computed tomography; MRI, magnetic resonance imaging.

[†] Ultrasound includes: abdominal and transvaginal ultrasound.

* Other blood tests includes: other tumour markers (n=8) for ovarian cancer and squamous cancer antigen (n=3) for cervical cancer.

[¶] Other includes: colposcopy (n=2) for cervical cancer and vulvoscopy (n=3) for vulval cancer.

Appendix: Gynaecological cancer follow-up survey of current practice

Introduction

Patients may appreciate the attention given to follow up after treatment for cancer yet the survival benefit of follow up is unclear. We are planning to review local practice to determine if follow up to detect recurrence at an early stage can improve survival. However a preliminary assessment of national practice would be ideal. A prospective study of follow up strategies may follow. We would appreciate a few minutes of your time as cancer specialists to complete the following questionnaire.

Questions

Q1. In which cancer network do you work?

Q2. Where do you work?

- i. Cancer Centre
- ii. Cancer unit
- iii. Other (please specify)

Q3. Please enter name of the hospital (s) at which you work? (Optional)

Q4. Is your work within surgical, medical or clinical oncology or another discipline?

- i. Surgical oncology
- ii. Medical oncology
- iii. Clinical oncology
- iv. Imaging
- v. Pathology
- iv. Other (please specify)

Q4.a. What is your profession?

- i. Medical
- ii. Nursing
- iii. Other (please specify)

Q5. Do you have a standard follow up protocol following completion of treatment for gynaecological cancer?

- i. Yes
- ii. No
- iii. Don't know

Q5a. Do you have a different protocol for different tumour sites e.g. cervix and ovary?

- i. Yes
- ii. No
- iii. Don't know

Q5b. Do you have a different protocol for different tumour types e.g. well or poorly differentiated?

- i. Yes
- ii. No
- iii. Don't know

Q5c. Does the routine follow-up involve visits to primary care?

- 1
- 2
- 3 i. Yes
- 4 ii. No
- 5 iii. Don't know
- 6

7 Q6. Do you have regular follow-up appointments? Regular follow-up appointments here means an
8 agreed schedule of visits from which the patient may discharge if she remains disease free after a
9 specified period of time.

- 10
- 11 i. Yes
- 12 ii. No
- 13 iii. Don't know
- 14

15 Q6a. If so, when can you book urgent follow-up appointments for symptomatic patients?

- 16
- 17 i. In less than 2 weeks
- 18 ii. 2-4
- 19 iii. 4+ weeks
- 20 iv. Don't know
- 21

22 Q6b. Who provides the follow-up?

- 23 i. Nurses
- 24 ii. Doctors
- 25 iii. Don't know
- 26 iv. Other (please specify)
- 27

28 Q7. Do you have telephone follow-up appointments? A telephone follow-up appointment is an
29 appointment pre-arranged for a member of the cancer team to contact the patient by telephone
30 without a need for the patient to attend hospital.

- 31
- 32
- 33 i. Yes
- 34 ii. No
- 35 iii. Don't know
- 36

37 Q7a. If so when can you book urgent follow-up appointments for symptomatic patients?

- 38
- 39 i. In less than 2 weeks
- 40 ii. 2-4
- 41 iii. 4+ weeks
- 42 iv. Don't know
- 43

44 Q7b. Who provides the follow-up?

- 45 i. Nurses
- 46 ii. Doctors
- 47 iii. Don't know
- 48 iv. Other (please specify)
- 49

50 Q8. Do you have patient initiated follow-up appointments? Patient initiated follow-up is when the
51 patient is not followed-up in secondary care but sees only if the patient requests (such as suspicion of
52 recurrent disease).

- 53
- 54
- 55 i. Yes
- 56 ii. No
- 57 iii. Don't know
- 58
- 59

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2
3 Q8a. Do you have a protocol for asking patients to self-refer with contact details (e.g. a secretary,
4 Macmillan Nurse or her GP)?
5

- 6 i. Yes
7 ii. No
8 iii. Don't know
9

10 Q8b. If so, can urgent appointments for symptomatic patients be booked? To see the patient

- 11 i. In less than 2 weeks
12 ii. 2-4
13 iii. 4+ weeks
14 iv. Don't know
15

16 Q8c. Who provides the follow-up?

- 17 i. Nurses
18 ii. Doctors
19 iii. Don't know
20 iv. Other (please specify)
21
22

23 Q9. Do you have a combination of regular follow-up, telephone follow up and/ or patient initiated
24 follow-up appointments?
25

- 26 i. Yes
27 ii. No
28 iii. Don't know
29

30 Q9a. Do you have a follow-up where patients attend either a medical or a nurse led clinic?

- 31 i. Yes
32 ii. No
33 iii. Don't know
34

35 Q9b. If yes, do you have a protocol to allocate patents to each clinic?

- 36 i. Yes
37 ii. No
38
39

40 Q10. Do you have combined follow-up clinics with other specialties (e.g. combined surgical and
41 medical oncology, surgical and clinical oncology clinics)?
42

- 43 i. Yes
44 ii. No
45 iii. Don't know
46

47 Q10a. If yes please specify

- 48 i. Clinical
49 ii. Medical
50 iii. Surgical oncology
51

52 Q11. During follow-up do you carry out certain blood tests (e.g. CA125), vault cytology or imaging such
53 as CT or MR routinely for cases at a certain time interval?
54

- 55 i. Yes
56 ii. No
57 iii. Don't know
58
59

1
2
3 Q11a. Ovary

- 4 i. Yes
5 ii. No
6

7 Q11a.i. Please provide details of which tests and when these are usually carried if possible
8

9 Q11b. Cervix

- 10 i. Yes
11 ii. No
12

13 Q11b.i. Please provide details of which tests and when these are usually carried if possible
14

15 Q11c. Endometrium

- 16 i. Yes
17 ii. No
18

19 Q11c.i. Please provide details of which tests and when these are usually carried if possible
20

21 Q11d. Vulva

- 22 i. Yes
23 ii. No
24

25 Q11d.i. Please provide details of which tests and when these are usually carried if possible
26

27 Q11e. Other

- 28 i. Yes
29 ii. No
30

31 Q11e.i. Please provide details of which tumour site(s)

32 Q11e.i.i. Please provide details of which tests and when these are usually carried if possible
33

34 Q12. After how many years of follow up are patients usually discharged?

- 35 i. 1
36 ii. 2
37 iii. 3
38 iv. 4
39 v. 5
40 vi. 6
41 vii. 7
42 viii. 8
43 ix. 9
44 x. 10
45 xi. 10+
46 xii. Never
47 xiii. N/A
48 xiv. Other(please specify)
49
50

51 Q13. If we were to develop a larger study would your centre be prepared to participate?
52

- 53 i. Yes
54 ii. No
55

56 Q13a. If so please add contact details here or email Simon Leeson
57
58
59
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Gynaecological cancer follow-up: National survey of current practice in the UK

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Gynaecological cancer follow-up national survey of current practice

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Key words: neoplasm, questionnaires, female continuity of patient care/standards, survivorship, neoplasm recurrence



Abstract

Objective

To establish a baseline of national practice for follow-up after treatment for gynaecological cancer.

Design

Questionnaire survey.

Setting

Gynaecological cancer centres and units.

Geographical location

UK

Participants

Members of the British Gynaecological Cancer Society and the National Forum of Gynaecological Oncology Nurses.

Interventions

A questionnaire survey.

Outcome measures

To determine schedules of follow-up, who provides it and what routine testing is used for patients who have had previous gynaecological cancer.

Results

A total of 117 responses were obtained; 115 (98%) reported hospital scheduled regular follow-up appointments. Two involved General Practitioners. Follow-up was augmented or replaced by telephone follow-up in 29 (25%) and patient initiated appointments in 38 responses (32%). A total of 80 (68%) cancer specialists also offered combined follow-up clinics with other specialties. Clinical examinations for hospital based follow-up were mainly performed by doctors (67% for scheduled regular appointments and 63% for patient initiated appointments) while telephone follow-up was provided in the majority by nurses (76%). Most respondents provided routine tests (76/117 (65%)), from which 66/76 (87%) reported carrying out surveillance tests for ovarian cancer, 35/76 (46%) for cervical cancer, 8/76 (11%) for vulval cancer and 7/76 (9%) for endometrial cancer. Usually patients were discharged after five years (82/117 (70%)), whereas three (3%) were discharged after four years, nine (8%) after three and one (1%) after two years.

Conclusions

Practice varied but most used a standard hospital based protocol of appointments for five years and routine tests were performed usually for women with ovarian cancer. A minority utilised nurse led or telephone follow-up. General Practitioners were rarely involved in routine care. A randomised study comparing various models of follow-up could be considered.

273 words

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4 or not-for-profit sectors.
5

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7

8 **Article summary**

9 **Article focus**

- 10 • Follow-up after treatment for cancer is a resource intense area of clinical practice which does
11 not have clear benefits for patients.
- 12 • Doctors and nurses involved in care for women with gynaecological cancer were invited to
13 respond to a questionnaire survey.
- 14 • A survey is presented of current follow-up after treatment for gynaecological cancer in the UK.

15 **Key messages**

- 16 • There is a variation of follow-up practice throughout the UK.
- 17 • A minority used nurse led or telephone follow-up as opposed to a conventional series of
18 hospital outpatient appointments to see a doctor.

19 **Strengths and limitations of this study**

- 20 • A strength is that this is the first study to report the extent of patient initiated, specialist nurse
21 or telephone follow-up for gynaecological cancer in the UK.
- 22 • Limitations are that four UK cancer networks did not respond, there were variations of
23 responses within networks and the response rate could not be calculated.

24 **Data sharing statement**

25 The raw data has been archived at NWOORTH Clinical Trials Unit and will be available to interested
26 researchers by agreement with the Principal Investigator.
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Introduction

Traditionally, patients who have had treatment for cancer are kept on regular review in hospital out-patient clinics for a period of between five to 10 years after completion of their treatment (Kew and Cruickshank, 2006). The aims may be to detect recurrence of tumour, to monitor late effects of treatment, to collect data and to offer patients an opportunity to raise concerns or anxieties arising from their cancer (Kerr-Wilson and McCrum, 1995; Kew *et al*, 2007; Kew *et al*, 2011). The assumption behind this approach is that early detection of recurrence will be of benefit to patients (Lajer *et al*, 2012; Vistad *et al*, 2012) and that monitoring side-effects and anxieties will allow helpful interventions that will improve quality of life.

Routine follow-up is a time-consuming and expensive process with many hundreds of patients attending clinics in each hospital each year at an NHS tariff of £118 per visit (Department of Health, 2011). In Wales alone we estimate the cost of this follow up is in excess of £1m annually. If the object is the early detection of recurrent disease, studies investigating recurrence for breast cancer reported most recurrences presenting between scheduled clinic appointments (Brøyn and Frøyen, 1982; Grunfeld *et al*, 1996; Pandya *et al*, 1985; Scanlon *et al*, 1980; Winchester *et al*, 1979; Zwaveling *et al*, 1987). This is also seen with patients having had treatment for early stage endometrial and cervical cancers (Shumsky *et al*, 1994; Vistad *et al*, 2011). Gynaecological patients may wait for their next routine appointment to disclose their symptoms (Olaitan *et al*, 2001). There is no prospective randomised evidence to suggest follow-up improves survival for ovarian cancer (Kew *et al*, 2011) or for cervical cancer (Elit *et al*, 2009). Also there is no evidence that intensive follow up improves survival for endometrial cancer (Agboola *et al*, 1997; Allsop *et al*, 1997; Gadducci *et al*, 2000; Owen and Duncan, 1996; Reddoch *et al*, 1995; Salvesen *et al*, 1997; Shumsky *et al*, 1994). A cost benefit analysis for endometrial carcinoma showed that one asymptomatic recurrence was detected in every 653 consultations (Salvesen *et al*, 1997). In a review of 12 studies, only 30% of endometrial cancer recurrences were asymptomatic and methods of follow-up were unrelated to survival (Fung-Kee-Fung *et al*, 2006). As around 20% of all female cancer survivors have had gynaecological malignancy a cost effective form of surveillance is important (Salani *et al*, 2011).

In clinical practice there appears to be no rationale available for any particular follow-up protocol (Sartori *et al*, 2010). As there is a lack of any demonstrable survival benefit for the follow-up of gynaecological cancer patients, other schedules of care could be considered. Telephone consultations can free oncologists' clinic time and is convenient for patients. Follow-up may be in primary care, a hospital based nurse led clinic, by telephone or at the request of the patient. Despite its place in standard healthcare the benefits of routine follow-up following treatment for gynaecological cancer has received little scrutiny and has rarely been subjected to formal assessment.

In order to determine a baseline of current practice for gynaecological cancer follow-up in the United Kingdom, we have performed a survey of cancer follow-up in gynaecological oncology. The intention is to investigate who performs follow-up, for what duration and how this is achieved to see if there is a possibility to improve the quality of care offered to patients after their cancer treatment.

Materials and methods

The follow-up survey was designed using the Bristol Online Survey (BOS) to provide electronic data capture and data management support to the questionnaire. The BOS is an easy-to-use survey tool, which allows developing, deploying and analysing surveys via the internet. The dataset was managed by the Information Systems Department at the North Wales Organisation of Randomised Trials (Bangor University). Data was anonymised and then exported to the databases held in SPSS™ (version 18.0; SPSS, Chicago, IL). The e-survey targeted gynaecological cancer secondary care practitioners (incorporating surgical and non-surgical specialists) in all cancer networks in the United Kingdom. It was available online using an electronic web link from June to September 2012. An initial invitation email and a reminder with the web link were sent through the Principal Investigator (PI) distribution list to all 441 members of the British Gynaecological Cancer Society (BGCS) and all 71 members of the National Forum of Gynaecological Oncology Nurses (NFGON). A news release published in June 2012 on the BGCS website also invited members to take part in the survey. It is possible that respondents could provide multiple replies but no two responses from the same network were identical.

The investigators in consultation with the BGCS and a patient representative designed the questionnaire which was organised around three themes (see questionnaire in appendix). The first comprised questions related to practice setting (i.e. organisation and hospital) and respondent characteristics (i.e. profession and medical speciality). The second comprised questions related to the use of standard protocols for follow-up. The bulk of the questionnaire addressed information about the different schedules of follow-up and which surveillance tests were used routinely in follow-up practices for different cancers. We listed four possible types of follow-up appointments; clinician led (traditional), nurse led, telephone follow-up and patient initiated follow-up. Telephone follow-up appointments were defined as a pre-arrangement for a member of the cancer team to contact the patient by telephone without a need for the patient to attend hospital. Patient initiated follow-up was defined as practice where the patient is not followed-up in secondary care but seen only if the patient requests or initiates a contact, for example if they are worried about a suspicion of recurrent disease.

Most answers were recorded as a binary variable (yes/no answer) with additional, open text box response options throughout the questionnaire for comments and alternative suggestions.

Data was collated and presented as numbers and a percentage of positive responses. For those questions composed of a subset of questions, the number of positive responses in the main question was used as the denominator for the subset. The geographical spread of responses was mapped by calculating responses also on a network basis, grouping all answers from respondents within their cancer networks. Any positive response within the group was accepted as a positive network response. Textual answers were categorised and counted.

Results

Sample size and respondents characteristics

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3 Responses were received from 118 experts in gynaecological cancer drawn from the membership of
4 the BGCS and NFGON. Because the survey was conducted online with the request to take part
5 distributed widely by email it is impossible to state how many had the opportunity to take part but did
6 not. Therefore the response rate has not been calculated. Nonetheless we received responses from
7 86% (24/28) of the cancer networks in England and all cancer networks in Scotland (three), Wales
8 (two), and Northern Ireland (one). Each responding cancer network provided between one to 14
9 responses. One response was received from a surgical oncologist based in Greece who has been
10 excluded from the study as the objective is assessing current practice of follow-up after gynaecological
11 cancer treatment in the UK. Of the 117 respondents included in the study, 71 (61%) worked in a
12 cancer centre, 32 (27%) in a cancer unit and 12 (10%) reported working in both. Eighty-eight (75%) of
13 the respondents specialised in surgical oncology. Fifteen (13%) specialised in clinical oncology and six
14 (5%) in medical oncology. The majority of the respondents (83 (71%)) were doctors while nurses
15 constituted less than a third of the sample (32 (27%)). Full results are presented in table 1.
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22 ***Standard follow-up protocols***

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24 All respondents with the exception of one surgical oncologist (116/117 (99%)) had a standard follow-
25 up protocol after completion of treatment. However all 30 networks providing responses had at least
26 one respondent reporting having protocols for follow-up. The vast majority of respondents provided
27 follow-up in secondary care, only two respondents (from different English cancer networks) reported
28 that visits to primary care are part of their follow-up routine.
29

30
31 Most 87/116 (75%) of the respondents reported using different follow-up protocols for different
32 tumour sites (eg. cervix and ovary) and 35/116 (30%) reported having different protocols for different
33 tumour types (eg. well or poorly differentiated). On a cancer network basis, different protocols for
34 different tumour sites were reported from 29/30 (97%) networks. Different protocols for different
35 tumour types were reported by respondents from 17/30 (57%) networks.
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40 ***Composition follow-up appointments***

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42 All respondents in our sample reported they follow-up patients after completion of gynaecological
43 cancer treatment. One hundred and fifteen (98%) reported hospital scheduled regular follow-up
44 appointments from which the patient may be discharged if she remains disease free after a specified
45 period of time. This follow-up was augmented or replaced by a telephone follow-up in 29 (25%) and
46 patient initiated appointments in 38 responses (32%). A combination of all three forms of follow-up
47 was reported by 11 respondents (a total of 54 respondents offered more than one modality of follow-
48 up). Of these 18/54 (33%) reported that patients have an opportunity to attend either a medical or a
49 nurse led clinic. However, 6/18 (33%) did not have a protocol to allocate patients to each clinic. For
50 patient initiated appointments, 10/38 (26%) did not have a protocol with contact details (eg. a
51 secretary, Macmillan nurse or General Practitioner) for self-referrals. A total of 80/117 (68%) cancer
52 specialists from 27/30 networks (90%) also offered combined follow-up clinics with other specialties
53 (eg. combined surgical and medical oncology or surgical and clinical oncology clinics).
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3 Virtually all respondents reported in the case of sudden events that symptomatic patients could
4 arrange an appointment in less than two weeks. Seven (6%) respondents from five different cancer
5 networks answered that their practices schedule urgent appointments in a period of two to four
6 weeks, from which two of them also scheduled urgent patient initiated appointments in the same
7 timeframe.
8

9
10 Follow-up in hospital was mainly performed by doctors (67% for scheduled regular appointments and
11 63% for patient initiated appointments) while telephone follow-up care was provided in its majority by
12 nurses (76%). Full details are illustrated in table 2.
13

14 15 ***Duration of follow-up and surveillance tests*** 16

17
18 The survey asked respondents whether they perform any type of routine surveillance test during
19 follow-up. Routine tests were requested by 65% (76/117) of respondents, from which 87% (66/76)
20 requested tests for ovarian cancer, 46% (35/76) for cervical cancer, 11% (8/76) for vulva cancer and
21 nine per cent (7/76) for endometrial cancer. In addition, respondents were asked to provide details of
22 when these tests are performed but only a few responses were obtained. Table 3 shows the
23 distribution of the different type of tests employed during follow-up.
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26
27 CA125 measurement was the most frequently used test (60/66 (91%)) during follow-up of ovarian
28 cancer patients. Other blood tests (8/66 (12%)), e.g. alpha-fetoprotein , carcino-embryonic antigen ,
29 CA19.9 and inhibin were also requested. The routine use of computed tomography and magnetic
30 resonance imaging (MRI) scans for ovarian cancer were reported by 9/66 (14%) of the respondents
31 (one respondent used both CT and MRI). Eight respondents stated the CA125 test is performed at each
32 visit. Another seven reported the CA125 is performed every three months for the first year after
33 completion of treatment, from which two reported they carry on with routine testing for the second
34 year and four up to the fifth year every six months.
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38 The use of MRI (15/35 (43%)) was the most common investigation employed in the follow-up of
39 cervical cancer with cervical or vaginal cytology being the second commonest method (14/35 (40%)).
40 There was a wide variety of tests (8/35 (23%)) reported in the follow-up of this type of cancer. Two of
41 the respondents stated they perform vault cytology for cervical cancer patients annually for a period
42 of five years following hysterectomy, while three specialists reported carrying out the test at six and
43 18 months post-treatment.
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46 Most respondents discharged their patients after five years of follow-up (82/117 (70%)), three (3%)
47 after four years, nine (8%) after three and one (1%) after two years whereas 22/117 (19%) of
48 respondents did not answer this question.
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50

51 52 **Discussion** 53

54
55 The current survey is the first evidence reporting the extent of patient initiated, specialist nurse or
56 telephone follow-up for gynaecological cancer in the UK. There were no respondents for four cancer
57 networks and because the survey was online, a response rate could not be calculated. Whilst we know
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3 the membership of the professional societies invited to respond, we do not know whether the entire
4 membership received or read their invitations to participate in our survey. Nonetheless a low response
5 rate could introduce a potential source of bias if the answers from respondents were not
6 representative of their relevant professional communities. Different protocols for different tumour
7 sites and types and the use of combined speciality follow-up clinics were more often reported from
8 network responses than for individual responses because positive network responses included
9 respondents with at least one positive response in each network. Unfortunately we could not calculate
10 the agreement level within networks because of the small numbers of respondents from each
11 network. The lack of consistency of responses within networks is again a potential source of error as
12 such responses may not accurately reflect local practice. We did not review the content of the follow-
13 up protocols and so we cannot verify if these variations represent locally approved practice within
14 each network. Network guidelines may be adapted for local use or not followed exactly, so variation
15 within networks would be expected. Our survey shows that all gynaecological cancer networks
16 providing responses have protocols for follow-up after treatment. Follow-up for patients treated for
17 gynaecological cancer is mainly performed by doctors in secondary care. Patient initiated follow-up
18 was offered by 32% of respondents and telephone follow-up was offered by 25%. A large minority of
19 patient initiated follow-up and combined follow-up schedules did not have protocols to guide practice.
20 The most common duration of routine follow-up was for five years. There are few routine tests
21 undertaken during follow-up to detect recurrence and they show no consistency particularly for
22 cervical cancer. Of the 35 respondents who requested tests for cervical cancer follow-up, 15 (43%)
23 requested MRI and 14 (40%) requested cytology. However, cervical cytology is recommended for the
24 follow-up of early stage cervical cancer if the cervix is conserved and was based upon expert opinion
25 rather than upon evidence (Luesley and Leeson, 2010) Variation in the routine use of tests during
26 follow-up is not surprising with the lack of evidence to guide clinical management. The exception is
27 CA125 testing following treatment for ovarian cancer where 52% of all respondents recommended
28 CA125 monitoring despite grade one evidence to demonstrate that routine CA125 measurements do
29 not provide a survival benefit with early treatment of relapse (Rustin *et al*, 2010). Furthermore, there
30 appears to have been no recent change of this practice in our survey, as monitoring with CA125
31 testing was reported in 24 of the 34 UK networks (71%) whereas 67% of networks recommended such
32 testing in an earlier survey (Kew and Cruickshank, 2006). Respondents were asked not to include tests
33 requested during treatment but tests could have been included as part of trial protocols. Vistad *et al*
34 (2012) also published results of a web-based survey of practice amongst gynaecological oncologists
35 across Europe and reported that 47% of the 375 respondents considered follow-up with General
36 Practitioners to be acceptable. Other options for care were not considered and the response rate was
37 thought to be below 20%.

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47 From other research, patients with previous ovarian cancer rated CA125 testing as the most important
48 part of follow-up (Kew *et al*, 2009). Furthermore knowledge of recurrence whether treatable or not
49 appears useful to patients (Papagrigoriadis and Heyman, 2003) and information should be provided to
50 detail the scope and limitations of follow-up (Kew *et al*, 2007). Rapid access to oncological assessment
51 at recurrence may be more important than offering frequent routine appointments (Shumsky *et al*,
52 1994; Gulliford *et al*, 1997). Knowing that different schedules of follow-up do not have an impact upon
53 survival, delegation of routine follow-up could be to other carers (Vistad *et al*, 2012). Follow-up may
54 be in primary care, a hospital based nurse led clinic, by telephone or at the request of the patient. An
55 individualised approach to follow-up is likely to be important to concentrate care for those perceived
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3 to be at a greater risk of recurrent disease or other issues of survivorship. This may include risk
4 stratification where there are effective interventions for physical, psychological and social issues as
5 well as needs assessments which are clearly patient centred as defined by the National Cancer
6 Survivorship Initiative (Watson *et al*, 2012). Follow-up has to be multidisciplinary, designed for
7 detection of morbidity as well as recurrence and with good communication between professional
8 groups. Informed patient choice regarding mode and frequency of follow-up is important. Reducing
9 the frequency of follow-up appointments may not place an increased demand upon unnecessary
10 patient initiated extra hospital appointments and patients may prefer fewer appointments (Gulliford
11 *et al*, 1997). The ideal time of advising a patient about a preferred form of follow-up is unclear but
12 may be shortly after all modalities of treatment have been completed.
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16 Healthcare providers should be informed by prospective data on the validity of alternative strategies
17 for gynaecological cancer follow-up which is already a minority part of current UK practice. The North
18 Wales Organisation for Randomised Trials in Health in collaboration with several leading
19 gynaecological oncologists has previously developed a proposal for a randomised study to assess the
20 value of hospital follow-up of endometrial cancer (Follow-up in Gynaecological Cancer Units: RCT for
21 Endometrium or FIGURE). The proposal was for a multicentre, randomised trial comparing standard
22 (hospital) follow-up with patient initiated review. The endpoints were to be quality of life and survival
23 with a planned recruitment of 2200 patients to detect an effect size of 0.2. Unfortunately, although
24 the proposal was well received, it was impossible to agree a level of funding to allow the study to
25 proceed. More recently the Endometrial Cancer Telephone Follow-up Trial (ENDCAT ISRCTN
26 75220876) has started. This is a study comparing traditional hospital follow-up with telephone follow-
27 up by specialist gynaecology oncology nurses with primary outcomes of psychological morbidity and
28 patient satisfaction. Again this is a randomised trial for endometrial cancers only and is at a single
29 centre. It is currently recruiting to schedule and is due to close in 2014. A Trial between Two Follow-up
30 Regimens with Different Intensity in Endometrial Cancer Treated Patients (TOTEM NCT00916708) is a
31 further ongoing but multicentre randomised trial in Italy, comparing overall survival, progression free
32 survival, complications, proportion of asymptomatic relapse and the proportion of patients completing
33 each regimen for follow-up. It is due to close in 2015.
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39 Our study has demonstrated that the vast majority of follow-up still reflects traditional patterns, with
40 only about a third of practitioners incorporating more flexible follow-up routines. However, the
41 evidence base for changing practice to a less intensive follow-up programme for gynaecological cancer
42 is poor and Vistad *et al* (2011) reported no randomised studies on this subject. A trial similar to an
43 early version of FIGURE should be revisited which included follow-up for more than one gynaecological
44 cancer site. In the present constrained financial environment, to continue to use patterns of follow-up
45 for gynaecological cancers which are neither evidence-based nor affordable is inappropriate. A
46 multicentre randomised controlled trial could assess the clinical benefits and costs of routine hospital
47 follow-up in comparison with the patient being empowered to choose her preferred format of follow-
48 up for most gynaecological cancers. The current survey may inform design of such a trial by providing
49 data from the UK concerning national practice.
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3252 words

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39 Authors' roles

40
41 Simon Leeson final manuscript preparation, review of data, design of questionnaire
42 Nick Stuart draft script development, design of questionnaire
43 Yvonne Sylvestre review of data
44 Liz Hall draft script development
45 Rhiannon Whitaker draft script development, review of data, design of questionnaire
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Table 1: Characteristics of respondents (N=117)

	N (%)
Region	
England	102 (87%)
Wales	7 (6%)
Scotland	5 (4%)
Northern Ireland	3 (3%)
Organisation	
Cancer centre	71 (61%)
Cancer unit	32 (27%)
Cancer unit & cancer centre	12 (10%)
Other ¹	2 (2%)
Specialty	
Surgical oncology	73 (62%)
Medical oncology	6 (5%)
Clinical oncology	15 (13%)
Surgical & medical oncology	6 (5%)
Surgical & clinical oncology	1 (1%)
Surgical, medical & clinical oncology	8 (7%)
Other ²	8 (7%)
Profession	
Medical	83 (71%)
Nursing	32 (27%)
Other ³	2 (2%)

1. Includes gynaecology unit in a chemotherapy centre (n=1) and hospital (n=1).

2. Includes clinical nurse specialist (n=2), nursing (n=2), gynaecology (n=2), gynaecology & surgical oncology (n=1) and pathology (n=1).

3. Includes consultant radiographer (n=1) and missing response (n=1).

Table 2: Type and frequency of occurrence of differing modes of follow-up

	Regular	Telephone	Patient initiated
Positive responses	115/117 (98%)	29/117 (25%)	38/117 (32%)
Urgent follow-up bookings			
< 2 weeks	108/115 (94%)	29/29 (100%)	35/38 (92%)
2 to 4 weeks	7/115 (6%)	0 (0%)	2/38 (5%)
Responsible for follow-up			
Doctors	77/115 (67%)	4/29 (14%)	24/38 (63%)
Nurses	0 (0%)	22/29 (76%)	2/38 (5%)
Doctors & nurses	36/115 (31%)	3/29 (10%)	11/38 (29%)
Other ¹	2/115 (2%)	1/29 (3%)	1/38 (3%)

1. Includes radiographer (n=1), consultant radiographer (n=1), for regular appointments; specialist radiographer (n=1) for telephone appointments and missing response (n=1) for patient initiated appointments.

Table 3: Frequency of surveillance tests reported by type of test and cancer type

	Ultrasound [†]	CA125	Other blood tests*	CT	MRI	Cytology	Other [¶]	Total
Ovarian	5	60	8	5	4	0	0	82
Cervical	1	0	4	0	15	14	3	37
Endometrial	1	1	0	0	1	1	0	4
Vulval	0	0	0	0	1	0	4	5

Key: CA125, cancer antigen 125; CT, computed tomography; MRI, magnetic resonance imaging.

[†] Ultrasound includes: abdominal and transvaginal ultrasound.

* Other blood tests includes: other tumour markers (n=8) for ovarian cancer and squamous cancer antigen (n=3) for cervical cancer.

[¶] Other includes: colposcopy (n=2) for cervical cancer and vulvoscopy (n=3) for vulval cancer.



Gynaecological cancer follow-up national survey of current practice

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Key words: neoplasm, questionnaires, female continuity of patient care/standards, survivorship, neoplasm recurrence



Abstract

Objective

To establish a baseline of national practice for follow-up after treatment for gynaecological cancer.

Design

Questionnaire survey.

Setting

Gynaecological cancer centres and units.

Geographical location

UK

Participants

Members of the British Gynaecological Cancer Society and the National Forum of Gynaecological Oncology Nurses.

Interventions

A questionnaire survey.

Outcome measures

To determine schedules of follow-up, who provides it and what routine testing is used for patients who have had previous gynaecological cancer.

Results

A total of 117 responses were obtained; 115 (98%) reported hospital scheduled regular follow-up appointments. Two involved General Practitioners. Follow-up was augmented or replaced by telephone follow-up in 29 (25%) and patient initiated appointments in 38 responses (32%). A total of 80 (68%) cancer specialists also offered combined follow-up clinics with other specialties. Clinical examinations for hospital based follow-up were mainly performed by doctors (67% for scheduled regular appointments and 63% for patient initiated appointments) while telephone follow-up was provided in the majority by nurses (76%). Most respondents provided routine tests (76/117 (65%)), from which 66/76 (87%) reported carrying out surveillance tests for ovarian cancer, 35/76 (46%) for cervical cancer, 8/76 (11%) for vulval cancer and 7/76 (9%) for endometrial cancer. Usually patients were discharged after five years (82/117 (70%)), whereas three (3%) were discharged after four years, nine (8%) after three and one (1%) after two years.

Conclusions

Practice varied but most used a standard hospital based protocol of appointments for five years and routine tests were performed usually for women with ovarian cancer. A minority utilised nurse led or telephone follow-up. General Practitioners were rarely involved in routine care. A randomised study comparing various models of follow-up could be considered.

273 words

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8 or not-for-profit sectors.

9
10 **Competing interests:** None declared

11 **Article summary**

12 **Article focus**

- 13 • Follow-up after treatment for cancer is a resource intense area of clinical practice which does
14 not have clear benefits for patients.
- 15 • Doctors and nurses involved in care for women with gynaecological cancer were invited to
16 respond to a questionnaire survey.
- 17 • A survey is presented of current follow-up after treatment for gynaecological cancer in the UK.

18 **Key messages**

- 19 • There is a variation of follow-up practice throughout the UK.
- 20 • A minority used nurse led or telephone follow-up as opposed to a conventional series of
21 hospital outpatient appointments to see a doctor.

22 **Strengths and limitations of this study**

- 23 • A strength is that this is the first study to report the extent of patient initiated, specialist nurse
24 or telephone follow-up for gynaecological cancer in the UK.
- 25 • LA-limitations are-is that four UK cancer networks did not respond, there were variations of
26 responses within networks and the response rate could not be calculated.

27 28 **Data sharing statement**

29 The raw data has been archived at NWORD Clinical Trials Unit and will be available to interested
30 researchers by agreement with the Principal Investigator.
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Introduction

Traditionally, patients who have had treatment for cancer are kept on regular review in hospital out-patient clinics for a period of between five to 10 years after completion of their treatment ([Kew and Cruickshank, 2006](#)). The aims may be to detect recurrence of tumour, to monitor late effects of treatment, to collect data and to offer patients an opportunity to raise concerns or anxieties arising from their cancer ([Kerr-Wilson and McCrum, 1995](#); [Kew et al, 2007](#); [Kew et al, 2011](#)). The assumption behind this approach is that early detection of recurrence will be of benefit to patients ([Lajer et al, 2012](#); [Vistad et al, 2012](#)) and that monitoring side-effects and anxieties will allow helpful interventions that will improve quality of life.

Routine follow-up is a time-consuming and expensive process with many hundreds of patients attending clinics in each hospital each year at an NHS tariff of £118 per visit (Department of Health, 2011). In Wales alone we estimate the cost of this follow up is in excess of £1m annually. If the object is the early detection of recurrent disease, studies investigating recurrence for breast cancer reported most recurrences presenting between scheduled clinic appointments (Brøyn and Frøyen, 1982; Grunfeld et al, 1996; Pandya et al, 1985; Scanlon et al, 1980; Winchester et al, 1979; Zwaveling et al, 1987). [This is also seen with patients having had treatment for early stage endometrial and cervical cancers \(Shumsky et al, 1994; Vistad et al, 2011\).](#) ~~G and gynaecological patients may wait for their next routine appointment to disclose their symptoms (Olaitan et al, 2001).~~ There is no prospective randomised evidence to suggest follow-up improves survival for ovarian cancer ([Kew et al, 2011](#)) ~~and retrospective data only to guide follow-up strategies~~ for cervical cancer ([Kew et al, 2011](#); Elit et al, 2009). Also there is no evidence that intensive follow up improves survival for endometrial cancer (Agboola et al, 1997; Allsop et al, 1997; Gadducci et al, 2000; Owen and Duncan, 1996; Reddoch et al, 1995; Salvesen et al, 1997; Shumsky et al, 1994). A cost benefit analysis for endometrial carcinoma showed that one asymptomatic recurrence was detected in every 653 consultations (Salvesen et al, 1997). In a review of 12 studies, only 30% of endometrial cancer recurrences were asymptomatic and methods of follow-up were unrelated to survival (Fung-Kee-Fung et al, 2006). As around 20% of all female cancer survivors have had gynaecological malignancy a cost effective form of surveillance is important (Salani et al, 2011).

In clinical practice there appears to be no rationale available for any particular follow-up protocol (Sartori et al, 2010). [As there is a lack of any demonstrable survival benefit for the follow-up of gynaecological cancer patients, other schedules of care could be considered. Rapid access to oncological assessment at recurrence may be more important than offering frequent routine appointments. Given that patients wish to be cured of their disease and that different schedules of follow-up do not appear to have an impact upon survival, delegation of routine follow-up could be to other carers.](#) Telephone consultations can free oncologists' clinic time and is convenient for patients. Follow-up may be in primary care, a hospital based nurse led clinic, by telephone or at the request of the patient. Despite its place in standard healthcare the benefits of routine follow-up following treatment for gynaecological cancer has received little scrutiny and has rarely been subjected to formal assessment.

In order to determine a baseline of current practice for gynaecological cancer follow-up in the United Kingdom, we have performed a survey of cancer follow-up in gynaecological oncology. The intention is

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7 to investigate who performs follow-up, for what duration and how this is achieved to see if there is a
8 possibility to improve the quality of care offered to patients after their cancer treatment.
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10 11 **Materials and methods**

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13 The follow-up survey was designed using the Bristol Online Survey (BOS) to provide electronic data
14 capture and data management support to the questionnaire. The BOS is an easy-to-use survey tool,
15 which allows developing, deploying and analysing surveys via the internet. The dataset was managed
16 by the Information Systems Department at the North Wales Organisation of Randomised Trials
17 (Bangor University). Data was anonymised and then exported to the databases held in SPSS™ (version
18 18.0; SPSS, Chicago, IL). The e-survey targeted gynaecological cancer secondary care practitioners
19 (incorporating surgical and non-surgical specialists) in all cancer networks in the United Kingdom. It
20 was available online using an electronic web link from June to September 2012. An initial invitation
21 email and a reminder with the web link were sent through the Principal Investigator (PI) distribution
22 list to all 441 members of the British Gynaecological Cancer Society (BGCS) and all 71 members of the
23 National Forum of Gynaecological Oncology Nurses (NFGON). A news release published in June 2012
24 on the BGCS website also invited members to take part in the survey. It is possible that respondents
25 could provide multiple replies but no two responses from the same network were identical.
26

27
28 The investigators in consultation with the BGCS and a patient representative designed the
29 questionnaire which was organised around three themes (see questionnaire in appendix). The first
30 comprised questions related to practice setting (i.e. organisation and hospital) and respondent
31 characteristics (i.e. profession and medical specialty). The second comprised questions related to the
32 use of standard protocols for follow-up. The bulk of the questionnaire addressed information about
33 the different schedules of follow-up and which surveillance tests were used routinely in follow-up
34 practices for different ~~type of~~ cancers. We listed four possible types of follow-up appointments;
35 clinician led (traditional), nurse led, telephone follow-up and patient initiated follow-up. Telephone
36 follow-up appointments were defined as a pre-arrangement for a member of the cancer team to
37 contact the patient by telephone without a need for the patient to attend hospital. Patient initiated
38 follow-up was defined as practice where the patient is not followed-up in secondary care but seen
39 only if the patient requests or initiates a contact, for example if they are worried about a suspicion of
40 recurrent disease.
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43 Most answers were recorded as a binary variable (yes/no answer) with additional, open text box
44 response options throughout the questionnaire for comments and alternative suggestions.

45
46 Data was collated and presented as numbers and a percentage of positive responses. For those
47 questions composed of a subset of questions, the number of positive responses in the main question
48 was used as the denominator for the subset. The geographical spread of responses was mapped by
49 calculating responses also on a network basis, grouping all answers from respondents within their
50 cancer networks. Any positive response within the group was accepted as a positive network
51 response. Textual answers were categorised and counted.
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Results

Sample size and respondents characteristics

Responses were received from 118 experts in gynaecological cancer drawn from the membership of the BGCS and NFGON. Because the survey was conducted online with the request to take part distributed widely by email it is impossible to state how many had the opportunity to take part but did not. Therefore the response rate has not been calculated. Nonetheless we received responses from 86% (24/28) of the cancer networks in England and all cancer networks in Scotland (three), Wales (two), and Northern Ireland (one). Each responding cancer network provided between one to 14 responses. One response was received from a surgical oncologist based in Greece who has been excluded from the study as the objective is assessing current practice of follow-up after gynaecological cancer treatment in the UK. Of the 117 respondents included in the study, 71 (61%) worked in a cancer centre, 32 (27%) in a cancer unit and 12 (10%) reported working in both. Eighty-eight (75%) of the respondents specialised in surgical oncology. Fifteen (13%) specialised in clinical oncology and six (5%) were specialised in medical oncology. The majority of the respondents (83 (71%)) were doctors while nurses constituted less than a third of the sample (32 (27%)). Full results are presented in table 1.

Standard follow-up protocols

All respondents with the exception of one surgical oncologist (116/117 (99%)) had a standard follow-up protocol after completion of treatment. However all 30 networks providing responses had at least one respondent reporting having protocols for follow-up. The vast majority of respondents provided follow-up in secondary care, only two respondents (from different English cancer networks) reported that visits to primary care are part of their follow-up routine.

Most 87/116 (75%) of the respondents reported using different follow-up protocols for different tumour sites (eg. cervix and ovary) and 35/116 (30%) reported having different protocols for different tumour types (eg. well or poorly differentiated). On a cancer network basis, different protocols for different tumour sites were reported from 29/30 (97%) networks. Different protocols for different tumour types were reported by respondents from 17/30 (57%) networks.

Composition follow-up appointments

All respondents in our sample reported they follow-up patients after completion of gynaecological cancer treatment. One hundred and fifteen (98%) reported hospital scheduled regular follow-up appointments from which the patient may be discharged if she remains disease free after a specified period of time. This follow-up was augmented or replaced by a telephone follow-up in 29 (25%) and patient initiated appointments in 38 responses (32%). A combination of all three forms of follow-up was reported by 11 respondents (a total of 54 respondents offered more than one modality of follow-up). Of these 18/54 (33%) reported that patients have an opportunity to attend either a medical or a

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7 nurse led clinic. However, 6/18 (33%) did not have a protocol to allocate patients to each clinic. For
8 patient initiated appointments, 10/38 (26%) did not have a protocol with contact details (eg. a
9 secretary, Macmillan nurse or General Practitioner) for self-referrals. A total of 80/117 (68%) cancer
10 specialists from 27/30 networks (90%) also offered combined follow-up clinics with other specialties
11 (eg. combined surgical and medical oncology or surgical and clinical oncology clinics).
12

13 Virtually all respondents reported in the case of sudden events that symptomatic patients could
14 arrange an appointment in less than two weeks. Seven (6%) respondents from five different cancer
15 networks answered that their practices schedule urgent appointments in a period of two to four
16 weeks, from which two of them also scheduled urgent patient initiated appointments in the same
17 timeframe.
18

19 Follow-up in hospital was mainly performed by doctors (67% for scheduled regular appointments and
20 63% for patient initiated appointments) while telephone follow-up care was provided in its majority by
21 nurses (76%). Full details are illustrated in table 2.
22
23

24 ***Duration of follow-up and surveillance tests***

25
26 The survey asked respondents whether they perform any type of routine surveillance test during
27 follow-up. Routine tests were requested by 65% (76/117) of respondents, from which 87% (66/76)
28 requested tests for ovarian cancer, 46% (35/76) for cervical cancer, 11% (8/76) for vulva cancer and
29 nine per cent (7/76) for endometrial cancer. In addition, respondents were asked to provide details of
30 when these tests are performed but only a few responses were obtained. Table 3 shows the
31 distribution of the different type of tests employed during follow-up.
32

33 CA125 measurement was the most frequently used test (60/66 (91%)) during follow-up of ovarian
34 cancer patients. Other blood tests (8/66 (12%)), e.g. alpha-fetoprotein , carcino-embryonic antigen ,
35 CA19.9 and inihibin were also requested. The routine use of computed tomography and magnetic
36 resonance imaging (MRI) scans for ovarian cancer were reported by 9/66 (14%) of the respondents
37 (one respondent used both CT and MRI). Eight respondents stated the CA125 test is performed at each
38 visit. Another seven reported the CA125 is performed every three months for the first year after
39 completion of treatment, from which two reported they carry on with routine testing for the second
40 year and four up to the fifth year every six months.
41

42 The use of MRI (15/35 (43%)) was the most common investigation employed in the follow-up of
43 cervical cancer with cervical or vaginal cytology being the second commonest method (14/35 (40%)).
44 There was a wide variety of tests (8/35 (23%)) reported in the follow-up of this type of cancer. Two of
45 the respondents stated they perform vault cytology for cervical cancer patients annually for a period
46 of five years following hysterectomy, while three specialists reported carrying out the test at six and
47 18 months post-treatment.
48

49 Most respondents discharged their patients after five years of follow-up (82/117 (70%)), three (3%)
50 after four years, nine (8%) after three and one (1%) after two years whereas 22/117 (19%) of
51 respondents did not answer this question.
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Discussion

The current survey is the first evidence reporting the extent of patient initiated, specialist nurse or telephone follow-up for gynaecological cancer in the UK. There were no respondents for four cancer networks and because the survey was online, a response rate could not be calculated. Whilst we know the membership of the professional societies invited to respond, we do not know whether the entire membership received or read their invitations to participate in our survey. Nonetheless a low response rate This could introduce a potential source of bias if the answers from respondents were not representative of their relevant professional communities. Different protocols for different tumour sites and types and the use of combined speciality follow-up clinics were more often reported from network responses than for individual responses because positive network responses included respondents with at least one positive response in each network. Unfortunately we could not calculate the agreement level within networks because of the small numbers of respondents from each network. The lack of consistency of responses within networks is again a potential source of error as such responses may not accurately reflect local practice. We did not review the content of the follow-up protocols and so we cannot verify if these variations represent locally approved practice within each network. Network guidelines may be adapted for local use or not followed exactly, so variation within networks would be expected. Our survey shows that all gynaecological cancer networks providing responses have protocols for follow-up after treatment. Follow-up for patients treated for gynaecological cancer is mainly performed by doctors in secondary care. Patient initiated follow-up was offered by 32% of respondents and telephone follow-up was offered by 25%. A large minority of patient initiated follow-up and combined follow-up schedules did not have protocols to guide practice. The most common duration of routine follow-up was for five years. There are few routine tests undertaken during follow-up to detect recurrence and they show no consistency particularly for cervical cancer. Of the 35 respondents who requested tests for cervical cancer follow-up, 15 (43%) requested MRI and 14 (40%) requested cytology. However, cervical cytology is recommended for the follow-up of early stage cervical cancer if the cervix is conserved and was based upon expert opinion rather than upon evidence (Luesley and Leeson, 2010) VSuch variation in the routine use of tests during follow-up is not surprising with the lack of evidence to guide clinical management. The exception is CA125 testing following treatment for ovarian cancer where 52% of all respondents recommended CA125 monitoring despite grade one evidence to demonstrate that routine CA125 measurements do not provide a survival benefit with early treatment of relapse benefit asymptomatic patients having had ovarian cancer (Rustin *et al*, 2010). Furthermore, there appears to have been no recent change of this practice in our survey, as monitoring with CA125 testing was reported in 24 of the 34 UK networks (71%) whereas 67% of networks recommended such testing in an earlier survey (Kew and Cruickshank, 2006). Respondents were asked not to include tests requested during treatment but tests could have been included as part of trial protocols. Vistad *et al* (2012) also published results of a web-based survey of practice amongst gynaecological oncologists across Europe and reported that 47% of the 375 respondents considered follow-up with General Practitioners to be acceptable. Other options for care were not considered and the response rate was thought to be below 20%. However there appears to be little or no evidence upon which to guide follow up for gynaecological malignancy from the survey by Vistad et al, the earlier survey from the UK (Kew and Cruickshank, 2006) and from our work.

From other research, patients with previous ovarian cancer rated CA125 testing as the most important part of follow-up (Kew *et al*, 2009). despite the knowledge that routinely measuring the CA125 value

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~~does not improve survival (Rustin *et al*, 2010).~~ Furthermore knowledge of recurrence whether treatable or not appears useful to patients (Papagrigroriadis and Heyman, 2003) and information should be provided to detail the scope and limitations of follow-up (Kew *et al*, 2007). Rapid access to oncological assessment at recurrence may be more important than offering frequent routine appointments (Shumsky *et al*, 1994; Gulliford *et al*, 1997). ~~Given that patients wish to be cured of their disease and knowing that different schedules of follow-up do not have an impact upon survival,~~ delegation of routine follow-up could be to other carers (Vistad *et al*, 2012). Follow-up may be in primary care, a hospital based nurse led clinic, by telephone or at the request of the patient. An individualised approach to follow-up is likely to be important to concentrate care for those perceived to be at a greater risk of recurrent disease or other issues of survivorship. This may include a risk stratification assessment where there are effective interventions for physical, psychological and social issues as well as needs assessments which are clearly patient centred as defined by the National Cancer Survivorship Initiative (Watson *et al*, 2012). ~~whilst bearing in mind that a minority of patients may be cured with further therapy.~~ Follow-up has to be multidisciplinary, designed for ~~detection risk of morbidity as well as~~ recurrence and with good communication between professional groups. Informed patient choice regarding mode and frequency of follow-up is important. Reducing the frequency of follow-up appointments may not place an increased demand upon unnecessary patient initiated extra hospital appointments and patients may prefer fewer appointments (Gulliford *et al*, 1997). The ideal time of advising a patient about a preferred form of follow-up is unclear but may be shortly after all modalities of treatment have been completed.

Healthcare providers should be informed by prospective data on the validity of alternative strategies for gynaecological cancer follow-up which is already a minority part of current UK practice. The North Wales Organisation for Randomised Trials in Health in collaboration with several leading gynaecological oncologists has previously developed a proposal for a randomised study to assess the value of hospital follow-up of endometrial cancer (Follow-up in Gynaecological Cancer Units: RCT for Endometrium or FIGURE). The proposal was for a multicentre, randomised trial comparing standard (hospital) follow-up with patient initiated review. The endpoints were to be quality of life and survival with a planned recruitment of 2200 patients to detect an effect size of 0.2. Unfortunately, although the proposal was well received, it was impossible to agree a level of funding to allow the study to proceed. More recently the Endometrial Cancer Telephone Follow-up Trial (ENDCAT ISRCTN 75220876) has started. This is a study comparing traditional hospital follow-up with telephone follow-up by specialist gynaecology oncology nurses with primary outcomes of psychological morbidity and patient satisfaction. Again this is a randomised trial for endometrial cancers only and is at a single centre. It is currently recruiting to schedule and is due to close in 2014. A Trial between Two Follow-up Regimens with Different Intensity in Endometrial Cancer Treated Patients (TOTEM NCT00916708) is a further ongoing but multicentre randomised trial in Italy, comparing overall survival, progression free survival, complications, proportion of asymptomatic relapse and the proportion of patients completing each regimen for follow-up. It is due to close in 2015.

Our study has demonstrated that the vast majority of follow-up still reflects traditional patterns, with only about a third of practitioners incorporating more flexible follow-up routines. However, the evidence base for changing practice to a less intensive follow-up programme for gynaecological cancer is poor and Vistad *et al* (2011) reported no randomised studies on this subject. A trial similar to ~~an early version of~~ FIGURE should be revisited ~~but which to included~~ follow-up for more than one gynaecological cancer site. In the present constrained financial environment, to continue to use

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patterns of follow-up for gynaecological cancers which are neither evidence-based nor affordable is inappropriate. A multicentre randomised controlled trial could assess the clinical benefits and costs of routine hospital follow-up in comparison with the patient being empowered to choose her preferred format of follow-up for most gynaecological cancers. The current survey may inform design of such a trial by providing data from the UK concerning national practice.

3252 words

For peer review only

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Nick Stuart	draft script development, design of questionnaire
Yvonne Sylvestre	review of data
Liz Hall	draft script development
Rhiannon Whitaker	draft script development, review of data, design of questionnaire

Table 1: Characteristics of respondents (N=117)

	N (%)
Region	
England	102 (87%)
Wales	7 (6%)
Scotland	5 (4%)
Northern Ireland	3 (3%)
Organisation	
Cancer centre	71 (61%)
Cancer unit	32 (27%)
Cancer unit & cancer centre	12 (10%)
Other ¹	2 (2%)
Specialty	
Surgical oncology	73 (62%)
Medical oncology	6 (5%)
Clinical oncology	15 (13%)
Surgical & medical oncology	6 (5%)
Surgical & clinical oncology	1 (1%)
Surgical, medical & clinical oncology	8 (7%)
Other ²	8 (7%)
Profession	
Medical	83 (71%)
Nursing	32 (27%)
Other ³	2 (2%)

1. Includes gynaecology unit in a chemotherapy centre (n=1) and hospital (n=1).

2. Includes clinical nurse specialist (n=2), nursing (n=2), gynaecology (n=2), gynaecology & surgical oncology (n=1) and pathology (n=1).

3. Includes consultant radiographer (n=1) and missing response (n=1).

Table 2: Type and frequency of occurrence of differing modes of follow-up

	Regular	Telephone	Patient initiated
Positive responses	115/117 (98%)	29/117 (25%)	38/117 (32%)
Urgent follow-up bookings			
< 2 weeks	108/115 (94%)	29/29 (100%)	35/38 (92%)
2 to 4 weeks	7/115 (6%)	0 (0%)	2/38 (5%)
Responsible for follow-up			
Doctors	77/115 (67%)	4/29 (14%)	24/38 (63%)
Nurses	0 (0%)	22/29 (76%)	2/38 (5%)
Doctors & nurses	36/115 (31%)	3/29 (10%)	11/38 (29%)
Other ¹	2/115 (2%)	1/29 (3%)	1/38 (3%)

1. Includes radiographer (n=1), consultant radiographer (n=1), for regular appointments; specialist radiographer (n=1) for telephone appointments and missing response (n=1) for patient initiated appointments.

Table 3: Frequency of surveillance tests reported by type of test and cancer type

	Ultrasound [†]	CA125	Other blood tests*	CT	MRI	Cytology	Other [¶]	Total
Ovarian	5	60	8	5	4	0	0	82
Cervical	1	0	4	0	15	14	3	37
Endometrial	1	1	0	0	1	1	0	4
Vulval	0	0	0	0	1	0	4	5

Key: CA125, cancer antigen 125; CT, computed tomography; MRI, magnetic resonance imaging.

[†] Ultrasound includes: abdominal and transvaginal ultrasound.

* Other blood tests includes: other tumour markers (n=8) for ovarian cancer and squamous cancer antigen (n=3) for cervical cancer.

[¶] Other includes: colposcopy (n=2) for cervical cancer and vulvoscopy (n=3) for vulval cancer.

Appendix: Gynaecological cancer follow-up survey of current practice

Introduction

Patients may appreciate the attention given to follow up after treatment for cancer yet the survival benefit of follow up is unclear. We are planning to review local practice to determine if follow up to detect recurrence at an early stage can improve survival. However a preliminary assessment of national practice would be ideal. A prospective study of follow up strategies may follow. We would appreciate a few minutes of your time as cancer specialists to complete the following questionnaire.

Questions

Q1. In which cancer network do you work?

Q2. Where do you work?

- i. Cancer Centre
- ii. Cancer unit
- iii. Other (please specify)

Q3. Please enter name of the hospital (s) at which you work? (Optional)

Q4. Is your work within surgical, medical or clinical oncology or another discipline?

- i. Surgical oncology
- ii. Medical oncology
- iii. Clinical oncology
- iv. Imaging
- v. Pathology
- iv. Other (please specify)

Q4.a. What is your profession?

- i. Medical
- ii. Nursing
- iii. Other (please specify)

Q5. Do you have a standard follow up protocol following completion of treatment for gynaecological cancer?

- i. Yes
- ii. No
- iii. Don't know

Q5a. Do you have a different protocol for different tumour sites e.g. cervix and ovary?

- i. Yes
- ii. No
- iii. Don't know

Q5b. Do you have a different protocol for different tumour types e.g. well or poorly differentiated?

- i. Yes
- ii. No
- iii. Don't know

Q5c. Does the routine follow-up involve visits to primary care?

- 1
- 2
- 3
- 4 i. Yes
- 5 ii. No
- 6 iii. Don't know

7 Q6. Do you have regular follow-up appointments? Regular follow-up appointments here means an
8 agreed schedule of visits from which the patient may discharge if she remains disease free after a
9 specified period of time.

- 10
- 11
- 12 i. Yes
- 13 ii. No
- 14 iii. Don't know

15 Q6a. If so, when can you book urgent follow-up appointments for symptomatic patients?

- 16
- 17
- 18 i. In less than 2 weeks
- 19 ii. 2-4
- 20 iii. 4+ weeks
- 21 iv. Don't know

22 Q6b. Who provides the follow-up?

- 23
- 24
- 25 i. Nurses
- 26 ii. Doctors
- 27 iii. Don't know
- 28 iv. Other (please specify)

29 Q7. Do you have telephone follow-up appointments? A telephone follow-up appointment is an
30 appointment pre-arranged for a member of the cancer team to contact the patient by telephone
31 without a need for the patient to attend hospital.

- 32
- 33
- 34
- 35 i. Yes
- 36 ii. No
- 37 iii. Don't know

38 Q7a. If so when can you book urgent follow-up appointments for symptomatic patients?

- 39
- 40
- 41 i. In less than 2 weeks
- 42 ii. 2-4
- 43 iii. 4+ weeks
- 44 iv. Don't know

45 Q7b. Who provides the follow-up?

- 46
- 47
- 48 i. Nurses
- 49 ii. Doctors
- 50 iii. Don't know
- 51 iv. Other (please specify)

52 Q8. Do you have patient initiated follow-up appointments? Patient initiated follow-up is when the
53 patient is not followed-up in secondary care but sees only if the patient requests (such as suspicion of
54 recurrent disease).

- 55
- 56
- 57
- 58 i. Yes
- 59 ii. No
- 60 iii. Don't know

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Q8a. Do you have a protocol for asking patients to self-refer with contact details (e.g. a secretary, Macmillan Nurse or her GP)?

- i. Yes
- ii. No
- iii. Don't know

Q8b. If so, can urgent appointments for symptomatic patients be booked? To see the patient

- i. In less than 2 weeks
- ii. 2-4
- iii. 4+ weeks
- iv. Don't know

Q8c. Who provides the follow-up?

- i. Nurses
- ii. Doctors
- iii. Don't know
- iv. Other (please specify)

Q9. Do you have a combination of regular follow-up, telephone follow up and/ or patient initiated follow-up appointments?

- i. Yes
- ii. No
- iii. Don't know

Q9a. Do you have a follow-up where patients attend either a medical or a nurse led clinic?

- i. Yes
- ii. No
- iii. Don't know

Q9b. If yes, do you have a protocol to allocate patents to each clinic?

- i. Yes
- ii. No

Q10. Do you have combined follow-up clinics with other specialties (e.g. combined surgical and medical oncology, surgical and clinical oncology clinics)?

- i. Yes
- ii. No
- iii. Don't know

Q10a. If yes please specify

- i. Clinical
- ii. Medical
- iii. Surgical oncology

Q11. During follow-up do you carry out certain blood tests (e.g. CA125), vault cytology or imaging such as CT or MR routinely for cases at a certain time interval?

- i. Yes
- ii. No
- iii. Don't know

1
2
3 Q11a. Ovary

4
5 i. Yes

6 ii. No

7
8 Q11a.i. Please provide details of which tests and when these are usually carried if possible

9
10 Q11b. Cervix

11 i. Yes

12 ii. No

13
14 Q11b.i. Please provide details of which tests and when these are usually carried if possible

15
16 Q11c. Endometrium

17 i. Yes

18 ii. No

19
20 Q11c.i. Please provide details of which tests and when these are usually carried if possible

21
22 Q11d. Vulva

23 i. Yes

24 ii. No

25
26 Q11d.i. Please provide details of which tests and when these are usually carried if possible

27
28 Q11e. Other

29 i. Yes

30 ii. No

31
32 Q11e.i. Please provide details of which tumour site(s)

33 Q11e.i.i. Please provide details of which tests and when these are usually carried if possible

34
35 Q12. After how many years of follow up are patients usually discharged?

36 i. 1

37 ii. 2

38 iii. 3

39 iv. 4

40 v. 5

41 vi. 6

42 vii. 7

43 viii. 8

44 ix. 9

45 x. 10

46 xi. 10+

47 xii. Never

48 xiii. N/A

49 xiv. Other(please specify)

50
51 Q13. If we were to develop a larger study would your centre be prepared to participate?

52 i. Yes

53 ii. No

54
55 Q13a. If so please add contact details here or email Simon Leeson